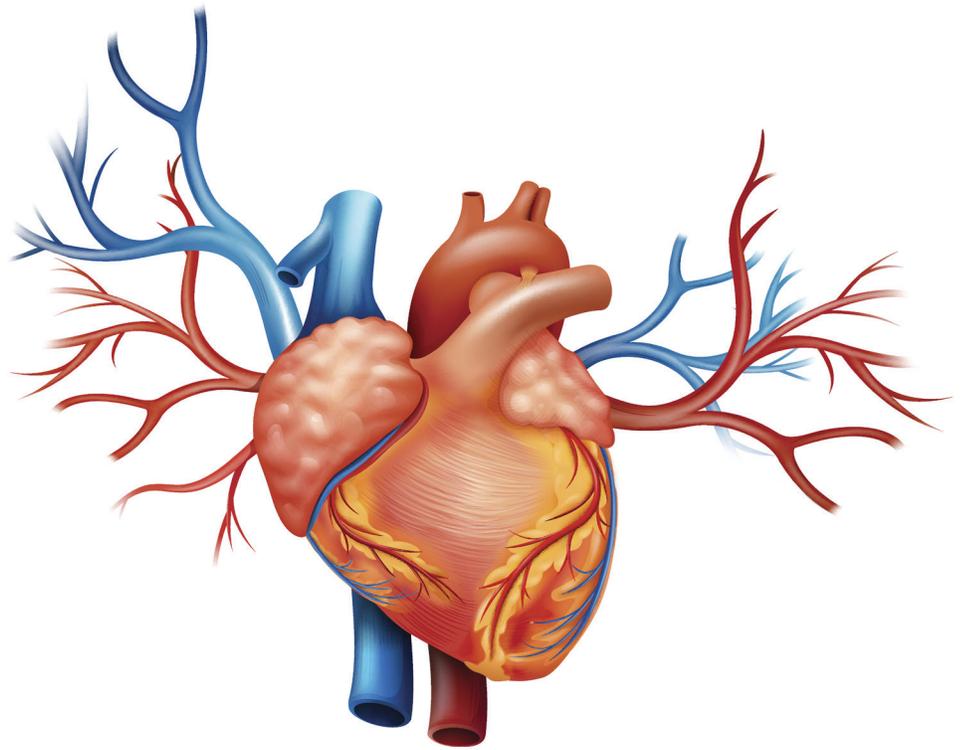


UW Medicine

# Congenital Heart Conditions

*A notebook for Heart Institute patients*







# Congenital Heart Conditions

## *Table of contents*

This notebook is divided into sections. Feel free to put the sections in the order that works best for you.

If you have any questions, please ask any of the Adult Congenital Heart Program team members listed on page 3 of the “About the Heart Institute” section.

### **Notebook Sections**

- Welcome
- About the Heart Institute
- Your Care Team
- Internet Resources
- Anticoagulation: What to Keep in Mind
- Diagnostic Tests
- Checking Your Blood Pressure
- How to Read Prescription Labels and Order Refills
- Lower Your Risk for Endocarditis
- If You Plan to Travel
- Advance Care Planning and Palliative Care
- Family Planning

### **Questions?**

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

Heart Institute Adult  
Congenital Heart Disease  
Program: 206.598.1764

Please share any ideas you have that will help us improve this notebook. Thank you for choosing the Heart Institute for your heart care needs.

*Materials by Medical Home, American Heart Association, and the Adult Congenital Heart Disease Center at the University of California at Los Angeles were used to help create this notebook.*





## Welcome

*To the Heart Institute at University of Washington Medical Center*

Welcome to the Heart Institute at University of Washington Medical Center (UWMC). It is our honor and privilege to take part in your care.

We created this notebook to help you learn about our Adult Congenital Heart Disease (ACHD) Program. We want to support you, your loved ones, and others who help in your care as you begin to work with your ACHD team. The notebook includes contact numbers for your team, an overview of how we serve our patients, information about diagnostic tests you may have, plus other helpful information.

Please read this notebook, and take notes on any questions you have. Feel free to contact our team with any questions or concerns.

With thanks,

The ACHD Team  
UWMC Heart Institute

### Questions?

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

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Congenital Heart Disease  
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*The Heart Institute is located at the University of Washington Medical Center - Montlake campus in Seattle.*



## About the Heart Institute

*At University of Washington Medical Center*

*This section of the Congenital Heart Conditions notebook gives basic information about your care at University of Washington Medical Center (UWMC), the Heart Institute, and helpful contact information.*

### What to Expect

The Heart Institute at UWMC uses a patient-centered, team approach to your care. That means a team of providers is devoted to your medical care, and you and your family are vital members of this team. All decisions about your heart care are made by you and your attending *cardiologist* (heart doctor).



*At UWMC, a team of providers is devoted to your medical care. You are a vital member of this team.*

During your time at UWMC, you will meet doctors in various stages of training. An Advanced Registered Nurse Practitioner (ARNP) may manage some of your care, along with your attending doctor. (See section entitled “Your Care Team.”)

### Protecting Your Healthcare Information

We cannot legally give information about your health and health care to anyone but you without your permission. But, you may give us the names of family members or friends who are allowed to receive this information.

### Your eCare Patient Portal

You can use eCare to:

- Access your medical records
- Send an email to your care team



*The Adult Congenital Heart Program at UWMC's Heart Institute was one of the first accredited centers of its kind in the U.S. To learn more about accreditation, visit [www.achaheart.org/provider-support/accreditation-program](http://www.achaheart.org/provider-support/accreditation-program).*

- Schedule appointments
- Request prescription refills
- And more!

To learn more about eCare, visit [www.uwmedicine.org/patient-resources/ecare](http://www.uwmedicine.org/patient-resources/ecare). If you have any trouble with your eCare account, call 206.520.8963 or send an email to [uwecare@uw.edu](mailto:uwecare@uw.edu).

## Health Insurance

We strongly advise you to keep your insurance coverage active. To help with this, you can:

- Work at a company that has good medical benefits
- Pay for short-term insurance called COBRA when you have gaps in insurance coverage
- Stay on your parents' insurance, if you are a student, or until you are 26 years old
- Use the Washington Health Plan Finder to find an insurance plan that works for you: [wahealthplanfinder.org](http://wahealthplanfinder.org)

Please 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, bring your parking ticket to the front desk of the clinic where you are being seen. Ask them to validate the ticket.

## Local Housing and Hotels

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

To learn more, visit [www.uwmedicine.org/patient-resources/lodging-options](http://www.uwmedicine.org/patient-resources/lodging-options), where you will find information on:

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

## Who to Contact

### Heart Institute

Appointment scheduling .....	206.598.4300
ACHD nurse ( <b>clinic hours only</b> , 8 a.m. to 5 p.m.) .....	206.598.0118
Patient Care Coordinator .....	206.598.3734
Patient Service Specialist.....	206.598.5264
ACHD Program Manager.....	206.598.1764
Heart Institute operator (toll-free).....	800.251.7695
For <b>non-urgent</b> issues only, email .....	sachs@uw.edu

### For urgent concerns after clinic hours:

UW Medicine Community Care Line .....	206.744.2500
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### UWMC

Operator .....	206.598.3300
Social Work and Care Coordination.....	206.598.4370
Anticoagulation Clinic .....	206.598.4874
UW Dentistry Campus Dental Center .....	206.685.8258
<i>Talk with your ACHD care team about low-cost or free dental clinics.</i>	
Radiology/MRI (Imaging Services) .....	206.598.6214
Nuclear Medicine .....	206.598.4240
Pulmonary Diagnostics for CPET or PFT testing.....	206.598.4265
Maternal and Infant Care Clinic .....	206.598.4070
Financial Services/Patient Access Department.....	206.598.4320
Medical Records .....	206.744.9000

### Harborview Medical Center

Operator .....	206.744.3000
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### Seattle Children's Hospital

Operator .....	206.987.2000
<i>Toll-free</i> .....	866.987.2000
Heart Center Clinic .....	206.987.2015
Heart Center Scheduling .....	206.987.2515

### Questions?

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

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## **Your Care Team** *At the ACHD Program*

*This handout lists the members of your care team at the Adult Congenital Heart Disease Program.*

### **Attending Doctor**

Your attending doctor is a heart specialist who is responsible for your care. The attending doctor oversees 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 or a Doctorate of 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.



*An advanced registered nurse practitioner (ARNP) works with your attending doctor to provide your care*

### **Fellow**

A fellow is a licensed doctor with 3 or more years of experience. A fellow is in training to be a specialist in some area of medicine.

### **Resident**

A resident is a licensed doctor in training, and has 1 to 3 years of experience.

### **Medical Student**

Medical students are in training to become doctors. They do not yet have their doctor's license.

## ACHD Program Team Members

### **Doctors**

*Adult Congenital Heart Service* ..... Eric Krieger, MD, Director  
Karen Stout, MD

Yonatan Buber, MD

Jason Deen, MD

Zachary Steinberg, MD

Jill Steiner, MD, MS

*Interventional Cardiology* ..... Thomas Jones, MD

Brian Morray, MD

Zachary Steinberg, MD

*Cardiac Surgery*..... Edward Verrier, MD

Christopher Burke, MD

Francisco Gensini, MD

Daniel Zimpfer, MD

*Electrophysiology* ..... Melissa Robinson, MD

Stephen Seslar, MD, PhD

*Heart Failure and Transplant* ..... April Stempien-Otero, MD

Elina Minami, MD

**Advanced Practice Providers**..... Elizabeth Bayley, MSN, ARNP

Jaimie Pechan, DNP, ARNP

**Registered Nurses** ..... Brenda O'Connell, RN, BSN

Ame Dohm, RN, MSN

Jessica Branco King, RN

**Patient Care Coordinator** ..... Cyndi DeVine

**Patient Service Specialist** ..... Dee Narvaez

**Program Manager** ..... Jilian Angiulo, BS

### **Questions?**

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

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Congenital Heart Disease  
Program: 206.598.1764



## Internet Resources

*For congenital heart patients*

*This section of the Congenital Heart Conditions notebook offers online resources that you may find helpful.*



### Heart Condition Resources

Adult Congenital Heart Association .... [www.achaheart.org](http://www.achaheart.org)

American Heart Association ..... [www.heart.org](http://www.heart.org)

Canadian Adult Congenital Heart Network ..... [www.cachnet.org](http://www.cachnet.org)

International Society for Adult Congenital Heart Disease ..... [isachd.connectedcommunity.org/home](http://isachd.connectedcommunity.org/home)

### Special Needs Resources in Washington State

Washington State Medical Home ..... [www.medicalhome.org](http://www.medicalhome.org)

Washington State Department of Social and Health Services ..... [www.dshs.wa.gov](http://www.dshs.wa.gov)

Transportation Services ..... [www.hca.wa.gov/health-care-services-supports/apple-health-medicaid-coverage/transportation-services-non-emergency](http://www.hca.wa.gov/health-care-services-supports/apple-health-medicaid-coverage/transportation-services-non-emergency)

The Arc Washington State ..... [www.arcwa.org](http://www.arcwa.org)

Washington State Health Exchange ..... [www.wahealthplanfinder.org](http://www.wahealthplanfinder.org)

### Americans with Disabilities Act (ADA) Resources

Americans with Disabilities Act ..... [www.ada.gov](http://www.ada.gov)

Healthy and Ready to Work ..... [www.hrtw.org](http://www.hrtw.org)

National Center on Workforce and Disability ..... [www.onestops.info](http://www.onestops.info)

## Career Counseling Resources

### **Access Washington**

<https://access.wa.gov/topics/employment/getjob.html>

A group of organizations dedicated to addressing Washington state's employment needs. They offer job search and placement services, job training, and many other job-related services.

### **Washington Assistive Technology Act Program**

<http://wataap.org>

This program offers assistive-technology resources.

### **The Work Site/Social Security Online**

[www.ssa.gov/work](http://www.ssa.gov/work)

Resources for those who are already receiving social security benefits, who want to return to work.

### **Questions?**

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

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## Anticoagulation

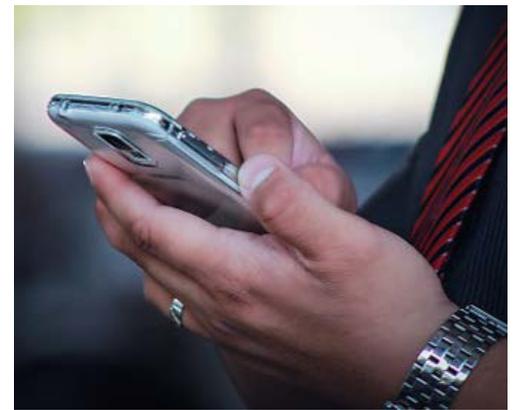
### *What to keep in mind*

*This section of the Congenital Heart Conditions notebook is for patients who are on anticoagulation medicines (blood thinners). It tells what to keep in mind and when to call the Anticoagulation Clinic.*

### When to Call

Call your anticoagulation clinic if:

- You miss a dose of your anticoagulant medicine.
- Your tablet or syringe looks different when you get your refill.
- Anyone tells you to stop or change your anticoagulation therapy.
- Your doctor or you change your current medicines. This includes prescription drugs, over-the-counter medicines, herbal or natural products, vitamins, and supplements.
- You have any unusual bleeding such as nosebleeds or other bleeding that lasts longer than 5 minutes, red or dark-brown urine, or red or dark, tarry stools.
- You have more bruising than usual after a fall or injury.
- You have a fever or an illness with vomiting, diarrhea, infection, pain, or swelling.
- You are scheduled for a surgery or other invasive procedure, or are having dental work.
- You are pregnant or planning to get pregnant.
- You have any questions about your anticoagulation therapy.



*Call your anticoagulation clinic if you have any questions or concerns.*

### Questions?

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

Heart Institute Adult  
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UWMC Anticoagulation Clinic:  
206.598.4874

**If you have an emergency,  
call 911 right away.**

**If you take warfarin:** Also call the clinic if you change your diet and eat more or less food that contains vitamin K.



## Diagnostic Tests

*For patients at the Heart Institute at UWMC*

*This section of the Congenital Heart Conditions notebook describes some of the diagnostic tests you may have. When you come for your clinic visit, your doctor may order one or more of these diagnostic tests.*

### Electrocardiogram

An *electrocardiogram* (EKG or ECG) test shows the electrical activity of your heart. It can help find abnormalities in the rhythm and structure of your heart.

This test uses *leads*, which are like stickers. The leads are placed on your arms, legs, and chest.

### Echocardiogram

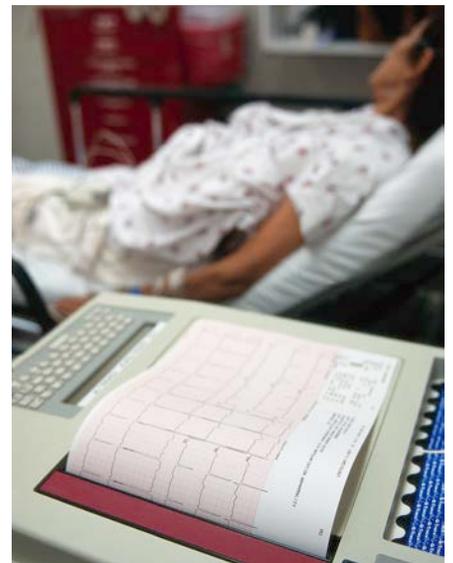
An *echocardiogram* checks the structure and function of your heart chambers and valves. It uses *ultrasound* (sound waves) to produce a picture of your heart.

During the test, the technician will move a hand-held wand across your chest to produce pictures of the different parts of your heart.

### Heart Monitors

A heart monitor is a device that you wear for 24 hours up to 30 days. The device shows changes in your heart's rhythm. You may not have any symptoms when your heart rhythm changes. But, you may also feel *palpitations* (rapid or strong heartbeat), dizziness, shortness of breath, or chest pressure.

You may want to keep a log of your symptoms while you are wearing the monitor. This can help your provider know if any rhythm changes occurred at the times you felt symptoms.



*An EKG test shows the electrical activity of your heart.*

There are 3 main types of heart monitors. **All monitors can be mailed back to UWMC when the test is over.**

- A **Holter monitor** has 7 leads that attach to your chest. It records all of your heart rhythms over a 24-hour period. **Please do not bathe or shower during the 24-hour test.**
- A **CAM monitor** is worn for 48 hours up to 7 days. It records all of your heart rhythms during that time. It is OK to take a shower during this time, but do not put the device under water.
- A **30-day event monitor** records your heart rhythm only when you activate it. Your doctor will tell you to push a button when you have palpitations, dizziness, shortness of breath, chest pressure, or other symptoms that cause you concern. You can remove this monitor when you want to shower or bathe.

## Stress Testing and Pulmonary Diagnostics

A stress test checks how your heart responds to physical stress, when your body needs more oxygen and blood flow. During the test, we will monitor your heart rate and electrical activity, blood pressure, and respiratory (breathing) rate.

Stress testing can be done with:

- Physical exercise on a treadmill or a stationary bike
- An echocardiogram before, during, and after stress (*stress echo*)
- A *cardiopulmonary exercise test* (CPET) or a *pulmonary function test* (PFT) to check your lungs

## Computed Tomography (CT) Scan

A CT scan uses special X-rays to create images of your heart and large blood vessels. If your doctor wants to use *contrast* (X-ray dye) for the test, it will be injected through an *intravenous* (IV) line in your arm.

## Magnetic Resonance Imaging (MRI)

An MRI uses a strong magnetic field and radio waves to create detailed images of your heart. It takes pictures from many different angles. You may need sedation (medicine to help you relax) or contrast through an IV for this test. MRI may not be the best test for you, or it may require extra planning, if you have an implanted device such as a pacemaker or implantable cardioverter defibrillator (ICD). Ask your doctor if you have any questions.

## Cardiac Catheterization

This procedure uses a small catheter (tube) that is placed into an artery or vein in the top of your leg, in your neck, or in your wrist. From there, the tube is threaded 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 as it pumps through your heart.

### Questions?

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

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## Checking 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 Machines

- Choose a blood pressure machine with an arm cuff, not a finger or wrist cuff.
- Make sure that the inflatable part of the cuff easily fits around the widest part of your upper arm. If the cuff is too large or too small, the readings will not be accurate.



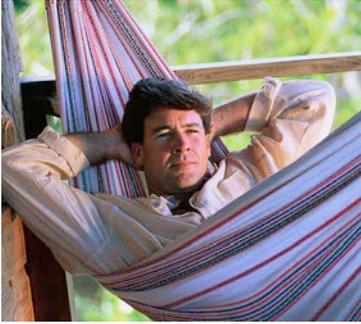
*Choose a blood pressure machine with an arm cuff.*

- 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. **You may also want to bring your cuff to every visit with our team, and check that it is accurate.**
- Inspect your blood pressure cuff often. 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.

### How to Get the Most Accurate Readings

To get the most accurate blood pressure readings:

- 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.
- 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.

## 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. Your upper arm should be at the same level as your heart.
- Put the cuff on your bare skin. Do not put it on over a sleeve.
- Wrap the blood pressure cuff snugly around your upper arm. The lower edge of the cuff should be 1 inch above the bend of your elbow.
- 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 provider if your blood pressure in one of your arms tends not to be accurate. 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

Keep a log of this information. Bring it to your next visit or report your numbers to your ACHD team.

### Questions?

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

Heart Institute Adult  
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## 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.

**UH OUTPATIENT PHARMACY**  
1959 N.E. PACIFIC STREET, SEATTLE, WA 98195  
ALLOW 48 HOURS FOR REFILL Phone: 206-598-4363

**1** → Rx: **A1324450**      ID No: 9699999 → **4**

**2** → Date: **6/20/12**      Dr: TEST, B MCISPROV → **5**

**TEST, PATIENT A**

TAKE ONE (1) TABLET EVERY SIX (6) HOURS AS NEEDED

**3** → **ASPIRIN \*\*EC\*\* 325MG TAB**      Y → **6**

QTY: 30 EA      Discard by: 6/20/13

Refill 0 Times      RPh:JWV \$ 4.50

06-20-1972      Orig Date: 06/13/12      2

WAAP: State or federal law prohibits transfer of this drug to any person other than the person for whom it is prescribed.

Sample prescription label

### Reading Prescription Labels

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

<b>1</b>	Prescription number
<b>2</b>	Date of your original prescription
<b>3</b>	Number of refills left on your prescription
<b>4</b>	Your UWMC patient number, also called your “U number”
<b>5</b>	Doctor who prescribed the medicine
<b>6</b>	Expiration date of the drug inside the container



*Check the label on your prescription bottle to see if you are able to get refills.*

## 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 says you can get refills: Call your pharmacist.
- The label shows “0” refills: You must talk with your pharmacist or doctor to renew your prescription.

### **When refilling your 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 healthcare provider if you have questions or concerns.

Heart Institute 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, how it occurs, how to prevent it, and signs to watch for.*

### What is endocarditis?

*Endocarditis* is an infection of the inner lining of the heart (*endocardium*) or heart valves. It is usually caused by bacteria (germs).

### How does it occur?

- Bacteria may grow in areas where there is *turbulent blood flow*, where blood flow speeds up or slows down. Bacteria may damage the heart tissue or spread to the body through the bloodstream.
- Valves, tubes, patches, or other materials that were placed during heart procedures can become infected.
- Skin infections or dental work can send germs into the bloodstream. (See “How to Prevent Endocarditis” on page 2.)

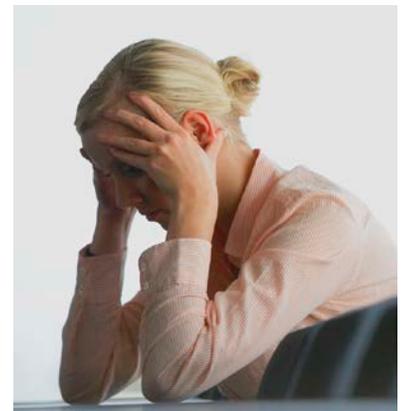
### How is it treated?

A person who has endocarditis usually needs to stay in the hospital for a long time. They are most often treated with *antibiotics* (medicines that kill germs). Sometimes, surgery may be needed.

### What are the signs?

Tell your healthcare provider if you have any of these signs of endocarditis:

- Ongoing fever, feeling ill, or cold symptoms that won't go away
- Pale skin
- Night sweats
- Unusual tiredness
- Weight loss
- Muscle or joint pain, or body aches



*Tell your provider if you have any signs of endocarditis.*

## How can I prevent endocarditis?

The best way to prevent endocarditis is to take good care of your teeth, skin, and nails.

### Teeth

Poor dental care or issues that occur during dental work are the main way bacteria get into the bloodstream. To avoid this problem:

- Keep up to date with teeth cleaning. We suggest seeing your dentist every 6 months. Visit your dentist sooner if you have a tooth that is broken, bleeding, or painful.
- For some heart conditions, we advise taking antibiotics before dental visits, especially if you have had:
  - Valve replacement(s)
  - A past episode of endocarditis
  - Recent heart surgery or procedure
  - Unrepaired heart defects or low oxygen saturation (*cyanosis*)

Ask your provider if you need to take antibiotics before dental visits. If you are planning to have a heart procedure, ask if you need clearance from your dentist first.

### Skin and Nails

Your skin is a natural barrier against infection. If that barrier is compromised, you may be at higher risk for infection (including endocarditis).

Prevent and treat cuts and scrapes, and avoid picking at your skin, nails, or scabs. If you notice any redness, swelling, or discharge from your skin or nails, contact your healthcare provider.

### Tattoos and Piercings

It is possible that getting tattoos, piercings, and other body art may increase your risk of endocarditis.

We do not usually advise taking antibiotics before getting tattoos or piercings. But, we suggest you proceed with caution. Choose businesses that use clean and safe practices. Always ask your provider if you have any questions.

### Questions?

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

Heart Institute Adult  
Congenital Heart Disease  
Program: 206.598.1764

## If You Plan to Travel

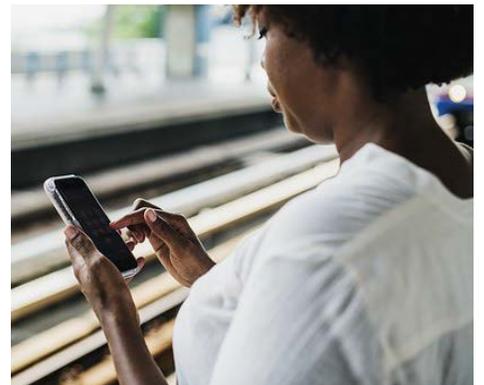
### *For congenital heart patients*

*This section of the Congenital Heart Conditions notebook details what to think about if you plan to travel.*

### Plan Ahead

If you are thinking about taking a trip, either in the U.S. or to another country, plan ahead:

- If you have any questions about your travel plans and how it may affect your heart, please contact your Adult Congenital Heart Disease (ACHD) care team.
- If you take any medicines, make sure you have refills ready before you leave on your trip.
- Ask your care team how to handle any environmental factors that could affect how your heart works (see “Environmental Factors and Your Heart” on page 2).
- If you have had a recent procedure, please ask your ACHD care team about how soon you can travel.
- In case you need to see a congenital cardiologist while you are on your trip, know how to find one.
- It may be important to make sure you have vaccines updated before you take your trip. Please check with your primary care provider (PCP) or travel clinic.



*Know how to find a heart doctor while you are on your trip.*

### Medicines and Travel

- You may need extra medicines or vaccines for some travel. Be sure to tell your PCP or travel clinic of any heart medicines you may be taking. It is important to avoid any drug interactions.

- Anticoagulant medicines such as warfarin (Coumadin) and apixaban (Eliquis) can increase your risk for bleeding. Keep this in mind if you plan on any activities while you are on your trip. Take preventive measures to avoid cuts and scrapes.

## Environmental Factors and Your Heart

- **High elevations:** Spending too much time at high elevations, where there is less oxygen in the air, might affect your heart. Please call the ACHD nurse if you have any questions about this.
- **Sun:** Sunscreen is vital for everyone. We strongly advise SPF 30 or higher for patients who recently had a *sternotomy* (surgery through the sternum, or breast bone). Too much sun can make incision lines darker.
- **Swimming:** If you recently had a sternotomy, do not go swimming or immerse your body in water until your doctor says it is OK.
- **Heat and cold:** Getting too hot or too cold can affect your blood pressure. Too much heat can cause dehydration. Please ask your nurse about how to best prepare and pack for high or low temperatures.
- **Scuba diving:** Please talk with your ACHD team before your trip if you have any questions about how scuba diving might affect your heart.

## Medical Care on Your Trip

- There are many adult congenital heart centers in the U.S. and Canada. The Adult Congenital Heart Association has a directory on their website: [www.achaheart.org](http://www.achaheart.org)
- If you travel outside the U.S., the Adult Congenital Heart Association has an online map and directory of adult congenital heart centers worldwide: [www.achaheart.org/media/2137/achatraveldirectory12edpf.pdf](http://www.achaheart.org/media/2137/achatraveldirectory12edpf.pdf)
- If you need urgent care while traveling and a care provider needs to know more about your heart history, have them call UWMC's Nurse Line at 206.744.2500. They should ask to page the ACHD provider on call.

### Questions?

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

Heart Institute Adult  
Congenital Heart Disease  
Program: 206.598.1764

## Advance Care Planning and Palliative Care

*For congenital heart patients*

*This section of the Congenital Heart Conditions notebook explains advance care planning and palliative care.*

### What is advance care planning?

It is always your choice whether or not to have certain types of care. But, there may be times when you are not able to tell your doctors what kind of care you want. This could happen if you become very sick, or you cannot speak for yourself for some reason.

Advance care planning lets you make decisions about the care you may want to receive at these times. Advance care planning gives you control over what might happen to you in the future. This can help ease anxiety.

It is best to do advance care planning before you become ill. As your health status and decisions change over time, you can review and update your care plan.

Care choices are very personal. Talk with your family, loved ones, and your healthcare provider about what you want.



*Talk with your loved ones and provider about your wishes for your care.*

### What is an advance directive?

An advance directive is a written form that tells your doctors and loved ones what care you want. It helps make sure that your wishes are carried out if you are not able to tell your care team what you want. There are different kinds of advance directives (see page 2).

Advance directives are legal documents. Each state has its own laws about how they are used. **Make sure you are using the right forms for the state where you live.**

Once you fill out an advance directive, share it with your family, loved ones, and care providers. Keep a copy with your other legal documents. You can change your advance directives over time, if you wish.

## What are some kinds of advance directives?

- A **living will** is a legal form. It tells the kinds of medical care you do or do not want to receive if you cannot express your wishes. It tells your loved ones whether you want to receive resuscitation, surgeries, end-of-life treatments, and other treatments.
- You can use a **durable power of attorney** or **healthcare proxy** to appoint another person to make decisions about your healthcare if you are not able to speak for yourself. This person helps with decisions that are not covered by your living will. But, your proxy cannot do anything that goes against your living will. Healthcare providers must follow the decisions of your proxy as if you were making the decisions.

Your proxy cannot be your doctor. You can change your proxy at any time, if you wish.

## What is palliative care?

Palliative care is special type of care for people who have a serious illness. It helps provide relief from the symptoms and stress of having a serious illness. Its goal is to improve quality of life.

Patients and their loved ones can benefit from palliative care at any stage of a serious illness. Palliative care can include hospice, but this is only one of many types of support you can ask for.

Talk with your provider about palliative care. If needed, they may refer you to our Palliative Care team.

When you talk with a member of our Palliative Care team, you can ask about ways to ease your symptoms or cope with stress. You can also talk about your healthcare goals and make decisions about treatments.

### Questions?

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

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## To Learn More

- Adult Congenital Heart Association: [www.achaheart.org/media/2055/qandaadvancedcareweb.pdf](http://www.achaheart.org/media/2055/qandaadvancedcareweb.pdf)
- Center to Advance Palliative Care: <https://getpalliativecare.org>
- Conversation Project: <https://theconversationproject.org>

Empower yourself by talking to your ACHD healthcare provider about advance care planning and palliative care!

## Family Planning

*For congenital heart patients*

*This section of the Congenital Heart Conditions notebook is for women with congenital heart disease who may want to have children.*

### If You Want to Try to Get Pregnant

Many women with congenital heart disease have successful pregnancies. Talk with your healthcare provider about your risks during pregnancy. Please know that if you have congenital heart disease:

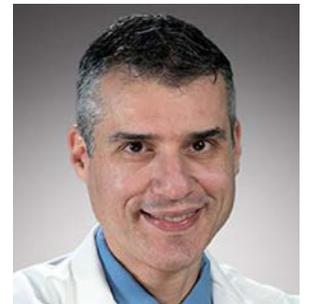
- Your children have a higher risk of having congenital heart disease.
- You may have a higher risk of heart problems during pregnancy, during delivery, and beyond.

If you decide you want to try to get pregnant:

- **First, talk with your cardiologist.** Your doctor may want to assess you. We want to make sure you have the safest pregnancy possible. There are only a few heart conditions that would cause your cardiologist to advise you not to have children.
- To make sure you and your baby are in the best health possible during the pregnancy and delivery, your provider prenatal care plan may include frequent doctor visits and careful monitoring.

### If You Are Already Pregnant

- **Call your cardiologist as soon as you can.** Your cardiologist may advise you to see an obstetrician who specializes in managing high-risk pregnancies.
- The UWMC Adult Congenital Heart Disease (ACHD) Program has a special pregnancy clinic. To learn more about this clinic, please call our nurses at 206.598.0118.



*Call your cardiologist as soon as you find out you are pregnant.*



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

## Adoption

If you are thinking about adopting a child, there are many helpful websites. Two of these are:

- Northwest Adoption Exchange: [www.nwae.org](http://www.nwae.org)
- Washington State Department of Children, Youth, and Families: [www.dcyf.wa.gov/services/adoption](http://www.dcyf.wa.gov/services/adoption).

## To Prevent Pregnancy

If you do not want to get pregnant, talk with your doctor about the best birth control methods for you. Some methods are safer for patients with a heart condition.

### Questions?

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

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