

Adults with congenital heart disease (CHD) should choose an insurance plan that will provide the coverage that they need for their special care. Choosing the right insurance policy is a very important decision. Figuring out how to do this can be complicated.

What are the different kinds of health insurance plans?

When looking at your options for insurance, you need to pay close attention to the plan's network of doctors. It is crucial to find one in which your adult congenital heart disease (ACHD) cardiologist is in network. You should also understand their policies for out-of-network care.

1. Preferred Provider Organization (PPO): These plans contract with certain medical providers, hospitals, etc. You pay less for care with in-network providers. Out-of-network services are offered at a higher cost. You can choose your primary care doctor. Referrals to a specialist are not required. While a PPO may cost more, they are more flexible than an HMO.
2. Health Maintenance Organization (HMO): Care is limited to providers who have a contract with the HMO. This network doesn't pay for care from outside providers, except in an emergency. You choose a primary care doctor from their network. You have to be referred by the primary care doctor to see a specialist. Although less expensive than a PPO, they are more restrictive in the kinds of services they cover.
3. Other networks include Point of Service (POS), Exclusive Provider Organization (EPO), Fee for Service (FFS) or Indemnity Plan and High Deductible Plans with a Health Savings Account. Refer to the glossary of terms for more information at www.achaheart.org/insurance.

Where do I find health insurance?

1. The first way is through your employer. Employers with 50 employees or more are required to offer insurance. These are known as group plans. They vary depending on employment benefit options.
2. Another avenue is by buying a Healthcare Marketplace plan. This allows you to purchase health insurance if you are not employed, if your employer doesn't offer insurance, or if you are not eligible for Medicaid or Medicare.
3. A third option is to purchase a private insurance plan through a broker or insurance company.



4. Government insurance plans are another option. They include Medicaid and Medicare. Medicaid is managed by states. Individuals with limited income and resources are eligible. Medicare is available to people with a qualifying work history who are 65 years of age or older, younger people with disabilities and people with end stage renal disease.
5. If you are between jobs, you may be eligible to continue taking your former employer's insurance by signing up for COBRA. You have to pay the full cost of the policy. It can be quite expensive.
6. Lastly, if you are still on your parent's health insurance plan, it may be best to stay on it until you turn 26.

Whatever you decide, it's important to stay insured at all times. If you go more than 63 days without insurance, you will lose some important protections.

Can I be turned down or charged more for insurance because I have congenital heart disease?

You cannot be turned down for health insurance because you have CHD (a pre-existing condition). You cannot be charged more either. Your insurer cannot refuse to pay. They also can't raise your rates based on your health. Your insurance cannot be canceled because of a diagnosis either.

How do I know what type of insurance policy to pick?

Before you decide on a health insurance policy, you need to consider answers to these questions:

1. How much does this health insurance policy cost a month? What is the premium?
2. Will my insurance start paying right away for my doctor's visits? Is there a deductible I must meet first and how much is it?

3. What is the total amount of my medical care that this plan will pay for? What is the out-of-pocket maximum I might have to pay in a year?
4. Will I pay a set price for a doctor's visit, procedure, and/or medication, or will I pay a percentage of the charge? What are the co-pays or co-insurance payments?
5. Does the policy pay for my medicines? Are mine in the drug formulary? What tier are my medications on?
6. Will the policy cover major surgery if I need it? Is there a co-insurance or co-pay involved with surgery and hospitalizations?
7. Can I pick my own doctors? Are all my doctors in network? Does the insurance policy allow me to get care from an adult congenital heart doctor? Does it allow me access to ACHA ACHD Accredited programs?
8. If I am traveling, can I see an in-network doctor or surgeon who knows about CHD?
9. What are the charges if I have to see an out-of-network doctor?
10. Do I need a referral to see an ACHD specialist?
11. If I have a family, will they also be covered? If so, how much will that change the cost and coverage?

Knowing all of this information will help you to better advocate for your care.

I don't understand these words! What in the world is a copayment? And how is it different from co-insurance? What are benefits?

Perhaps the best place to start is learning the language. An understanding of copayment, co-insurance and many other words will help with the more complicated insurance issues. Knowing them will put you on an even playing field with the insurers. You should start with some of the most basic terms, available at www.achaheart.org/insurance.

What are the essential benefits of all health insurance policies?

Essential health benefits include 10 categories of services that must be covered under the Affordable Care Act:

1. Ambulatory patient services
2. Emergency services
3. Hospitalization
4. Pregnancy, maternity, and newborn care
5. Mental health and substance use disorder services
6. Prescription drugs
7. Rehabilitative and habilitative services
8. Laboratory services
9. Preventive and wellness services and chronic disease management
10. Pediatric services, including oral and vision care
 - Adult dental and vision coverage aren't essential health benefits

What if I can't afford to buy insurance?

If you are unable to pay for medical care, don't be afraid to call the hospital or doctor's office billing department. They will often work with you so you can pay a reduced price or even get free care. They will help you with a payment plan. You can also talk to the ACHD program social worker who may be able to help you apply for either Medicaid or Medicare or other local programs.

Can I appeal the decision of my insurer if I don't agree or I think they are wrong?

Yes, you have the right to appeal. There are two types of appeals: internal and external.

Every insurer has its own internal review process for appeals. You should call your insurance company as soon as possible after your claim is denied to find out what their appeal process is. It's imperative to be aware of the timeline, to stay organized and to provide the correct paperwork. As an ACHD patient, you want to submit the following information for the appeal:

1. Copies of your medical records that relate to your CHD.
2. A link to the ACHD Guidelines, highlighting the area(s) that relate directly to your appeal.
3. A letter from your ACHD provider supporting the need for the test/procedure/medication they have denied.

You also should do the following:

1. Ask for a peer-to-peer review between your ACHD team and the insurer's team.
2. Request a call with the Medical Director of the insurance company.

If your appeal is denied internally, you may request an external review by a third party reviewer. The insurance company has to accept the decision of the external reviewer.

What are some tips for talking to my insurer?

1. If there is an issue with your coverage, you need to contact your insurer as soon as you can.
2. Anything you discuss by telephone should be followed up by email and saved. If you can't email, keep written notes in a safe place. This includes conversations in which you are told a procedure, medication etc. is covered. Be sure to document the name of the person you spoke with.
3. If in doubt, call someone else to confirm information.
4. Get a second opinion if necessary.

In summary, as a congenital heart patient, it is critical to have health insurance. You need to look carefully at the different options and pick a policy that meets your needs. When picking a policy, make sure your ACHD specialist and ACHD program are part of the network.