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Understanding Health Insurance

Health insurance can be confusing. Keep reading to learn more, understand your choices, and find help.

[READ MORE >](#)





1. What is health insurance?

Health insurance is a way to pay for medical expenses. You can use health insurance when you are sick or injured. You can also use health insurance for regular check-ups and preventative screenings.

WHY DO I NEED HEALTH INSURANCE? >

2. Why do I need health insurance?

Healthcare expenses can add up when you have a rare disease. People use health insurance to help pay for expenses such as, but not limited to:¹

- Doctor visits
- Tests
- Surgeries
- Medicine
- Emergency services
- Pediatric care

WHAT TYPES OF HEALTH INSURANCE ARE THERE? >



3. What types of health insurance are there?

There are several types of health insurance:

1. Commercial, Private, and Employer-Based Plans:²

This is health insurance that you buy from a health insurance company. Many people buy it as a group through their employer. You may also buy it individually.

Each plan is different. Plans have different requirements about how much you have to pay toward your healthcare expenses. If you buy health insurance through your job, you are usually able to add your spouse and children to that plan.

2. Marketplace Plans:²

The Health Insurance Marketplace is where you can buy health insurance online. It was created by the Affordable Care Act (ACA). It helps people who can't get insurance from their job and people who can't get Medicare or Medicaid.

Marketplace insurance plans offer different levels of coverage. They may be different in each state. Visit [healthcare.gov](https://www.healthcare.gov) to find plans in your state.

WHAT TYPES OF HEALTH INSURANCE ARE THERE? (CONT.) >

Affordable Care Act: The Affordable Care Act (ACA) is a healthcare reform law passed by the U.S. Congress. It became a law in 2010.⁵

(cont.)

3. What types of health insurance are there?

3. Government Assistance Programs:²

Medicare, Medicaid, and the Children's Health Insurance Program (CHIP) are government programs for people who can't work or can't afford other types of health insurance.

- a. **Medicare:** A federal health insurance program for people age 65 and older and people under age 65 with certain disabilities. To find out if you can apply, **visit <https://www.medicare.gov/eligibilitypremiumcalc/>**.³
- b. **Medicaid:** A state health insurance program for people with a low income. It provides low-cost medical benefits. Each state has different rules about who can get Medicaid. To find out if you're eligible, **visit <https://www.healthcare.gov/medicaid-chip/>**.⁴ People with certain illnesses may be able to get Medicaid even if they do not have a low income. They must apply for a waiver. See the next section to learn more about waivers.
- c. **Children's Health Insurance Program (CHIP):** A federal and state health insurance program that offers insurance for some children (up to age 19). This is for some families who cannot afford to buy insurance but earn too much to get Medicaid. CHIP is different in each state. To find out if you can apply, **visit <https://www.insurekidsnow.gov/coverage/index.html>**.⁴

To learn more about these programs and find out if you can apply, **visit <https://www.medicaid.gov/medicaid/index.html>**.²

WHAT IF I'M NOT ELIGIBLE FOR MEDICAID? >

4. What if I'm not eligible for Medicaid?

You may be able to get a **Medicaid waiver** if you don't have insurance, need special services, or need help paying for healthcare. Even if a child is covered by insurance already or is not from a low-income family, he or she might be able to get a Medicaid waiver in some cases.

Insurance might not cover everything that children living with rare diseases need. Medicaid waivers may help provide services like private nursing and specialized therapies.

A social worker or care manager can help you with your state's Medicaid waiver. To learn more about Medicaid waivers, [visit **http://www.kidswaivers.org/full-list/**](http://www.kidswaivers.org/full-list/).⁶

WHAT TYPES OF EXPENSES MIGHT INSURANCE HELP WITH? >



5. What types of expenses might insurance help with?

Your benefits depend on your plan, but insurance usually helps provide coverage for the following:¹






1. Outpatient care (when you don't stay in a hospital)
2. Emergency room visits
3. Inpatient care (when you stay in a hospital)
4. Care before and after your baby is born
5. Mental health and substance abuse services
6. Prescription drugs
7. Care to help you recover from an injury or deal with a disability or chronic condition (including physical and occupational therapy)
8. Lab tests
9. Preventive services
10. Dental care and vision care for children (adults usually have separate dental and vision insurance)

WHAT DETERMINES HOW MUCH I PAY FOR PRIVATE HEALTH INSURANCE? >



6. What determines how much I pay for private health insurance?¹

To determine your premium, there are five factors that insurance companies consider:¹

-  1. Age
-  2. Location
-  3. Tobacco use
-  4. Individual vs. family plan
-  5. Level of coverage

HOW ELSE CAN I GET HELP WITH MEDICAL COSTS? >

Premium: This is the amount of money you pay for a health insurance policy or plan.¹

7. How else can I get help with medical expenses?

There are other ways to get help with medical expenses, including assistive equipment, travel for appointments, and in-home care services, if you or someone you care for is living with a rare condition. Patient assistance programs can also help with copays. To learn more about getting help with medical expenses, ask your patient advocacy organization.

To learn more about health insurance and medical care expenses for people living with rare conditions, look at these resources:

- Global Genes' Navigating Health Insurance: https://globalgenes.org/wp-content/uploads/2017/01/Navigating-Health-Insurance_DIGITAL_spread_op.pdf
- National Organization for Rare Diseases (NORD)'s State Health Insurance Information: <https://rarediseases.org/for-patients-and-families/information-resources/patient-and-caregiver-resource-center/state-health-insurance-information/>

IMPORTANT HEALTH INSURANCE TERMS >

8. Important Health Insurance Terms

REFERENCES >

Open Enrollment Period: This is the time when you can sign up for a health insurance plan. This usually happens before January 1, but there are different deadlines depending on your employer and what type of insurance you choose.⁷

Premium: This is the amount of money you pay for a health insurance policy or plan.¹

Deductible: This is how much money you may need to pay for healthcare expenses before your insurance starts to cover them. Your deductible amount depends on your plan. Not all types of insurance have a deductible so check with your insurance provider.¹

Copayment (Copay): This is the fee you may need to pay for a healthcare visit or a prescription medicine. When you pay a copay, it goes toward your deductible, if you have one. The amount is listed in your health insurance plan, so you know what to expect.¹

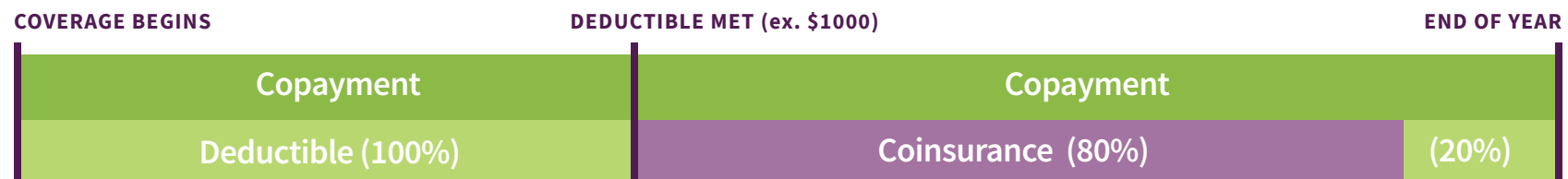
Coinsurance: This is the share of expenses that you have to pay after you have met your deductible. For example, you might have to pay 20% while your insurance company pays 80%.¹



YOU PAY



YOUR INSURANCE PAYS



The above illustration shows **one** example of how an insurance plan would help cover healthcare costs. There are many different potential scenarios.

9. References



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