Your Life, Your Rights Chapter 4: Healthcare

Easy Read Guidebook





How to Use This Guidebook



This Guidebook is about your right to healthcare.



Healthcare is care or treatment you get from a health provider to feel your best.



Everyone has the right to healthcare.



This guidebook will share your healthcare rights and the laws that protect them.



Some of this information may make you sad or upset.



Stop reading this guidebook and ask for support if you start to feel upset.



You do not have to read this guidebook all at once.



It is okay to take breaks as you read this guidebook.

Part 1: Right to Healthcare



You have the right to healthcare.



Healthcare includes your **physical health**, or how well your body and organs are working.



Healthcare also include your **mental health**, or how well your mind is working so you can think and act.



Everyone has the right to healthcare so they feel good and live their best life.

Your Healthcare rights include:



1. Be treated with dignity and respect.



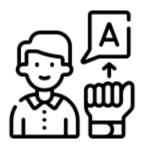
This means people listen to your wants, wishes, and feelings about your healthcare.



When doctors and nurses start working they agree to a set of rules about treating people.



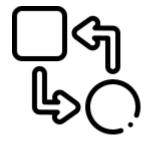
Treating people with dignity and respect is one of the rules providers agree to.



2. Have free access to an interpreter.



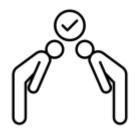
An <u>interpreter</u> helps two or more people who speak a different language talk to each other.



The interpreter will take what is said in one language and change it to another language.



This includes sign language and spoken language.



Interpreters help you and your doctor understand each other so you get the help you need.



A free interpreter must be available to you at the hospital if you need it.



This right is protected by the Civil Rights Act and Americans with Disabilities Act (ADA).



These laws protect your right to access hospital services in the language you use.



3. Have the same treatment options as everyone else.



<u>Treatment options</u> are the different things your doctor can do to help you feel better.



Treatment options may be medicine, therapy, and more.



This includes emergency or life saving treatment.



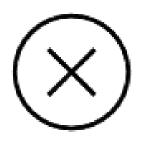
This right is protected by Section 504 of the Rehabilitation Act.



Section 504 of the Rehabilitation Act is a law that makes sure things are not denied to people with disabilities.



Under this law hospitals must give people the same treatment options no matter their disability.



Health providers cannot deny a person a type of treatment because they have a disability.



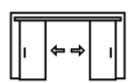
4. Have the same access to healthcare as everyone else.



Access to healthcare means you can go to doctor appointments and get care when you need it.



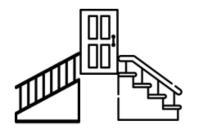
The two laws that protect your right to access are the Americans with Disabilities Act (ADA) and Rehabilitation Act.



Under these laws hospitals must make their services open to all people no matter what.



Access includes having close parking or space to be dropped off close to the building if you need it.



It means the building has stairs or ramps and different ways to open the door.



Access also includes exam rooms with accessible medical tools.



<u>Accessible medical tools</u> are tools doctors use to care for people with disabilities.



Another important part to your right to access is being able to pay for healthcare.



<u>Health insurance</u> is a plan you have with a company to help pay for healthcare.



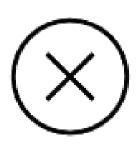
The Affordable Care Act (ACA) is a law that helps make sure everyone can get health insurance they can afford.



Health insurance helps people get healthcare by paying for health services.



5. Make an appointment with your doctor when you need to.



No one should stop you from meeting your doctor when you are sick or want to talk about your health and care plans.



6. Talk to your doctor about starting or stopping treatment.



This is true for treatments that can heal you or save your life.



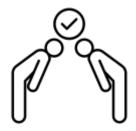
This is also true for treatments that are "elective," which are not for a life-saving reason.



It is okay to ask questions or to want to learn about different parts to your health.



The choice to start or stop treatment is yours.



Your doctor and the people you trust should respect your choice even if they do not agree with you.



7. Make decisions about your health.



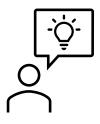
This includes picking your own doctor and deciding what you want them to help you with.



8. Get health education to help you make choices.



You must give informed consent for all health care choices you make.



<u>Informed consent</u> is knowing the good and bad things that come with a choice you make.



Your doctor must help you reach informed consent.



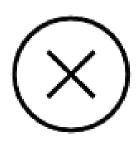
Your doctor will do this by helping you understand the good and bad things that may come from a choice.



When you understand what can come from a choice you are better able to make the best choice for you.



9. Get emergency care when you need it even if you can't pay.



The emergency room providers cannot turn you away from treatment.



This right is protected by the Emergency Medical Treatment and Labor Act (EMTALA).



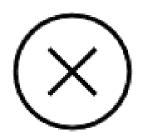
Under this law hospitals must help people in the emergency room even if they have no insurance or money to pay.



10. To have your personal health record kept private.



<u>Personal health records</u> are the doctor notes or test results about your health and treatment.



The hospital cannot share anything about you unless you say it is okay or are in an emergency.



The law that protects this right is the Health Insurance Portability and Accountability Act (HIPAA).



11. You decide who can have access to your health information.



When someone has access to your health information they can talk to your doctor any time.



They can also get a copy of your health records.



The choice to give someone access is up to you.



12. You can get your medical records at anytime.



Medical records are your personal health records.



The law that protects this right is the **Cures Act**.



Under this law hospitals must give you your records and not hide anything from you.

Part 2: Advocating For Fair Treatment



It is important to know what your healthcare rights are.



Knowing your rights is the first step to advocate for yourself.



Advocating for yourself means to stick up for yourself.

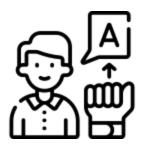


In this section you will learn examples of how you can advocate for you right to fair treatment.

Real world examples:



1. You tell your doctor's office you need an interpreter for your appointment next week, but the office tells you no.



This breaks your right to have free access to an interpreter.



Under the law you must have equal access to communication.



You can ask to speak to someone else like a patient advocate to make sure you get an interpreter.



2. You visit your new doctor's office but you can't get in with your wheelchair because there are stairs.



This breaks your right to have the same access to healthcare as everyone else.



Public places like hospitals must have ways for all people to enter them.



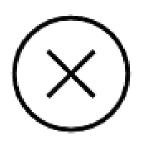
You can let the office know they are not accessible and find a different office to go to.



3. Your doctor signs you up for physical therapy even though you asked to try yoga instead.



This breaks your right to make decisions about your health.



No one should make choices for you without talking to you first.



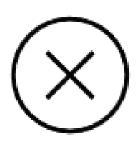
You can thank your doctor but tell them you will not go to physical therapy because you want to try yoga.



4. Your family member gets a copy of your doctor's notes without asking you first. They are not your guardian.



This breaks your right to have your personal health record kept private.



It is against the law for the hospital to share information about you without asking you.



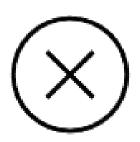
You can report this to the hospital and Office for Civil Rights (website).



5. You ask your doctor's office for a copy of your records but they say you can't have them.



This breaks your right to get your medical records at anytime.



Being denied your records for no reason is against the Cures Act.



You can tell the office about the Cures Act and ask to talk to someone else to help you get what you need.

Part 3: Protecting Your Rights



You are the best person to protect your right to healthcare.



Contact the Rhode Island Attorney
General's Office to file a healthcare
complaint by phone at (401) 274-4400
x1896 or online at www.riag.ri.gov/.



For legal help and training on your rights, contact Disability Rights Rhode Island by phone at (401) 831-3150 or by visiting their website at www.drri.org.



Remember, you have the right to fair treatment and to live your best life.

Part 4: Resources



In this section you will find a list of websites that were visited to make this guidebook.



You will also find helpful tools other agencies made about healthcare rights.



You can explore these resources to learn more about your healthcare rights.



Once you learn your rights you will be better able to protect them.

Websites used to make this guidebook:

Section 504 of the Rehabilitation Act of 1973 Part 84 Final Rule: Fact Sheet

- Website: <u>www.hhs.gov</u>
- Visit this website to learn more about the Rehabilitation Act.
 There were new changes to this law in 2024. The changes improve fair treatment for people with disabilities.

ADA Standards for Accessible Design

- Website: <u>www.ada.gov</u>
- Visit this website to learn more about the Americans with Disabilities Act (ADA). This webpage focuses on how public places must have buildings people with disabilities can enter and move around in easily.

AMA Principles of Medical Ethics

- Website: <u>AMA Code of Medical Ethics</u>
- This website lists the principles or rules doctors agree to follow. These rules guide how doctors take care of people.

Access to Medical Care for Individuals with Mobility Disabilities

- Website: <u>www.ada.gov</u>
- Visit this website to learn more about the laws hospitals and doctor offices must follow. The laws focus on fair access to healthcare.

About the Affordable Care Act

- Website: <u>www.hhs.gov</u>
- This website explains the Affordable Care Act. This law helps make sure everyone can get health insurance they can afford.

Emergency Medical Treatment & Labor Act (EMTALA)

- Website: www.cms.gov
- Visit the website to learn about your rights to healthcare in emergencies. The focus is on the Emergency Medical Treatment and Labor Act (EMTALA).

Summary of the HIPAA Privacy Rule

- Website: www.hhs.gov/hipaa
- Visit this website to learn more about your right to privacy in healthcare. This website focuses on the Health Insurance Portability and Accountability Act (HIPAA).

Cures Act Overview

- Website: www.rmf.harvard.edu
- This website focuses on the Cures Act. This law protects your right to have a copy of your medical records.

Resources from other agencies:

A Self-Advocate's Guide to Medicaid

- Website: https://autisticadvocacy.org
- This guide explains Medicaid. Medicaid is a joint federal and state program. It helps cover costs for healthcare.

Access, Autonomy and Dignity: A Series on Reproductive Rights and Disability Justice

- Website: <u>www.nationalpartnership.org</u>
- This website shares guidebooks about your right to sexual health and reproductive justice. <u>Reproductive justice</u> is the right to make choices about your body and have children or not.

Advocacy brief: Disability and the Right to Bodily Autonomy

- Website: <u>www.unfpa.org</u>
- On this website you will find a guidebook about your right to make choices about your body and stay safe. The guidebook is available in other languages.

Affordable Care Act Toolkit for Self-Advocates

- Website: <u>www.autisticadvocacy.org</u>
- This toolkit explains the Affordable Care Act (ACA). The ACA
 is a law that helped people get health insurance that they
 could afford. People need health insurance to pay for
 healthcare services they need.

The National Roadmap

- Website: www.inclusivecareroadmap.org
- This roadmap was made for healthcare providers. People with intellectual and/or developmental disabilities (I/DD) helped create this roadmap. The roadmap shares tips with healthcare providers to take better care of people with I/DD.

Our Bodies, Our Rights: What's Going On at the Supreme Court?

- Website: <u>www.autisticadvocacy.org</u>
- This guidebook explains the rights people have to make choices about their bodies. It focuses on laws that protect a person's right to have a baby or not when they are pregnant.