

Patients' Rights and Responsibilities

An Easy-to-Read Guide
For People Taking
Medicine

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About Project MED

“Project MED” stands for **M**edication **E**Ducation. The Project MED Group has written a series of eight education booklets about medicines. These booklets will help you if you have learning problems, reading problems, or problems understanding why you are taking medicine. These booklets will also be useful to you if English is not your main language. Parents, guardians, and other care givers might like to read these booklets too.

Our goal was to write the information in plain words. When we cannot avoid using a hard-to-read word, we give you help in pronouncing (pronounced) the word. We also describe what the hard-to-read word means in parentheses ().

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For People Taking Medicine

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Are You a Patient?

Do you see a doctor for problems with your feelings or behavior? Do you have trouble doing a job or school work? Do you take medicine for any of these problems? If you answered yes to any of these questions, then this booklet can help you.

This booklet is about your **rights** and **responsibilities** (ree-spon-seh-BILL'-it-ees) as a patient. *Rights* are what you can expect when you see a doctor or go into a hospital or clinic for treatment. We will talk about the things that your doctor should do and should not do when he or she sees you. We will also talk about your responsibilities to the doctor. *Responsibilities* are things that you should do to help the doctor make you feel better. Following what your doctor says will make sure that any medicines given to you will help you. It is very important that you and your doctor work together as a team.

Your Rights

As a patient, you have many important rights. Let's talk more about each one of your rights.

1. Right to Informed Consent

Most adults have the right to informed consent.



This means that your doctor should give you *information* (in-fer-MAY'-shun) or tell you why you are feeling bad. Your doctor should tell you what can be done to make you feel better. Then you have the right to say yes or no to the treatment the doctor suggests.

What Kind of Things Should the Doctor Tell You?

- The doctor should tell you what is making you feel bad. For example, the doctor might tell you that you became angry with other people too easily. The doctor might tell you that you act too sad.
- The doctor should tell you about the treatment that he or she thinks is best for you. The doctor might want you to take some medicine.
- The doctor should tell you the good things that he or she hopes will happen to you with treatment. The good things are called *benefits*.

- The doctor should tell you about any bad things that might happen to you with treatment. The bad things are called *risks*, or *side effects*. Bad things don't happen to everyone, but they could happen to you.
- The doctor should try to answer any questions that you have about treatment or medicines. You might want to know more about the risks or side effects that can happen when you take medicine. Sometimes side effects are a problem. For example, some medicines might make you feel tired during the day. Sometimes side effects can even be helpful. Some medicines might make it easier for you to fall asleep at bedtime, even though the medicine was given to you for a different reason.
- The doctor should tell you how sure he or she is that a medicine will work for you. Medicines do not always work the same way for everyone. You might want to ask your doctor what the "odds" are that a medicine will work for you.
- The doctor should tell you if the treatment might cause lasting changes. These changes might be good or bad.
- The doctor should tell you what could happen if you do not take the treatment. The results might be very serious (big) or they might be minor (little).
- The doctor should tell you if there are other treatments that could work for you. The doctor should tell you the good things and bad things about these treatments, too.

Voluntary (VOL'-un-tair-ee) Decision

After the doctor has given you all of this information, you have to decide if you want to take the treatment or medicine. You should be able to decide if you want the treatment without feeling like somebody is making you do it. No one should try to force a treatment on you. This should be your own decision. This means that you are making a *voluntary* (VOL'-un-tair-ee) decision.

If you do not understand everything that the doctor tells you, ask someone for help before you make up your mind. Talk with other people you know and trust, like your parents, other family members, or friends.

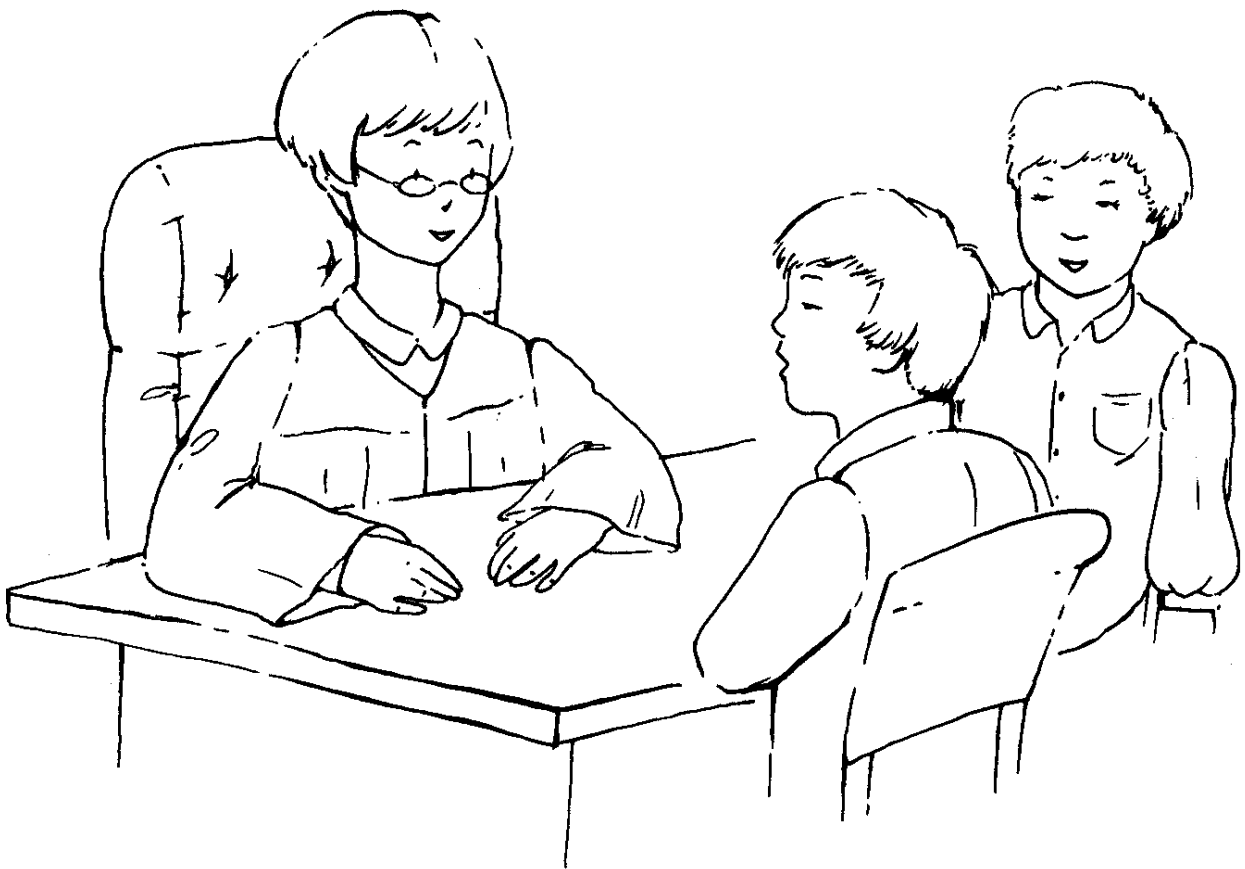
If you still do not know if you want or need the treatment, you can ask for a second opinion (o-PIN'-yen). You can see another doctor to see what he or she thinks is best for you. If two different doctors tell you the same thing, it should be easier for you to make the right decision about your treatment.

Competency (KOM'-peh-ten-see)

Competency is a legal word that means a patient is able to make very important decisions about his or her life. In order to be competent, a patient must be able to:

- understand the information that the doctor tells him or her.
- understand how serious the problem is.
- understand the treatments that the doctor suggests.
- understand the results (consequences) of his or her decision.
- tell the doctor *yes* or *no* when asked if he or she wants the treatment.

Often, young people (less than 18 years old) are considered not competent. Sometimes people older than 18 years may not be competent, if they cannot understand these points. In some cases, a judge might tell the patient that he or she is not competent. A judge might do this because the patient can't understand the decisions that need to be made.



If a judge says a patient is not competent, the doctor must give all of the information we talked about before to the patient's guardian (GARD'-ee-en).

Assent (uh-SENT')

Assent means that you should be told about your treatment, even if you are not competent. Assent means that you agree with (accept) the treatment plan that your doctor and care giver make. If you help decide what treatment to take, you will feel like a member of the team. You will have a say in your future. If you agree to your treatment, you might try harder to make the treatment work. For example, you will try to take your medicine at the right time every day.

2. Right to Refuse Treatment

You or your guardians have a right to say no to treatment. If you are not competent and you say no to treatment, then three things might happen.

- Your guardian could make the decision (say yes or no) for you.
- A group of people might work together to make the decision for you.
- The decision might be made in court, with a judge and someone speaking for you.

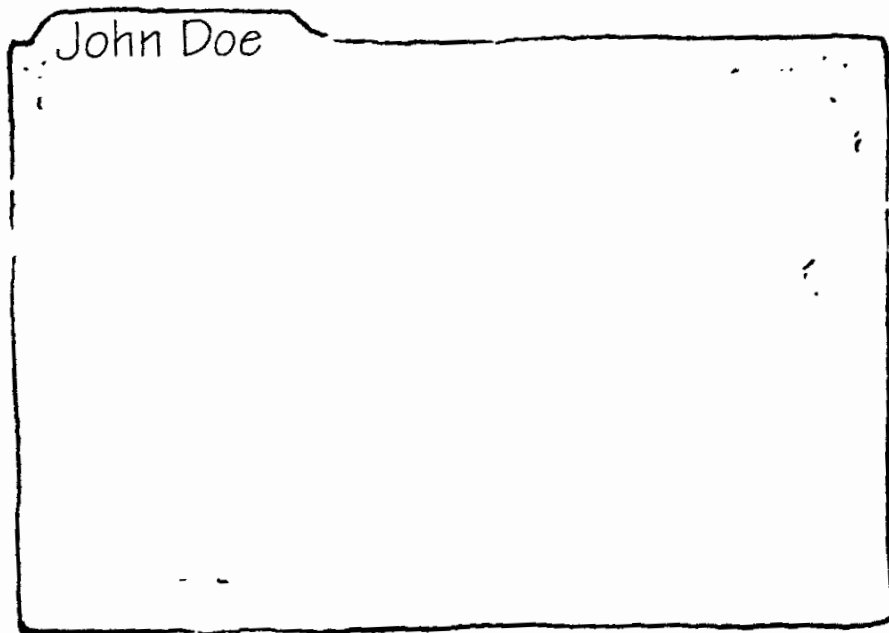
Most of the time, treatment is not given to a person who says no. Your Doctor and your guardian should try to find another treatment that you like better.

3. Right to Confidentiality (kon-fih-den-chee-AL'-i-tee)

You might tell your doctor things about yourself that you do not want anyone else to know. When you tell the doctor you don't want other people to know these things, you are *talking in confidence* (KON'-fi-h-dens). This might help the doctor learn more about you. It will also help the doctor give you the best treatment. Most of the time, the things you tell your doctor are private (secret). The doctor is not allowed to talk about them or tell other people. This is called *confidentiality*.

There are times when your doctor does not have to keep information secret. The doctor does not have to keep the information secret if:

- it has been decided that you are not competent.
- you tell your doctor that you may hurt yourself or you may hurt other people.
- there is an *emergency* (ee-MUR'-jen-see). An emergency is when fast action is needed to stop something really bad from happening.



4. Right to See Your Records

In some cases, you have a legal right to look at the information that the doctor has about you. This information might include the notes that the doctor takes during your visit. It may include results of tests that the doctor ordered. In the United States, about half of the states have laws that say you can see your medical records if you want to.

To find out about the laws where you live, call the medical society (group) in your state. To find this number, call the American Medical Association's main office in Chicago, Illinois: (800) 621-8335. You can also find this information online at the following website address:

<http://www.ama-assn.org/ama/pub/about-ama/our-people/the-federation-medicine/state-medical-society-websites.shtml>.

5. Continued Medical Care

If you start treatment with a doctor, he or she must continue to treat you, or the doctor must try to find someone else to treat you. He or she can't just stop seeing you without trying to find another doctor for you.

How to Complain

Now you know about your rights. What should you do if a doctor or hospital doesn't follow or respect your rights?

The first thing you should do is stay calm. You might feel mad, but try not to lose your temper. Talk to the person who is not following (respecting) your rights. This person might be your doctor or dentist, for example. If the problem happened in a hospital, talk to the patient representative (rep-reh-ZEN'-tuh-tiv) at the hospital. The patient representative will work with you to make sure your rights are being followed.



If someone is not respecting your rights, they need to stop doing this. Be strong and stick to the facts when you talk to this person. If the person still does not listen to what you are saying, write a letter to that person telling them what your complaint (kom-PLAINT') is. If you have trouble writing this letter, ask someone to help you.

If this does not work, there are other things that you can do. You can tell your complaint to someone else, and they may be able to help you.

- Call your local (state) medical society. Call the American Medical Association's main office in Chicago, Illinois: (800) 621-8335. They can tell you the number to call for your area.
- Call the state agency that licenses doctors. To find this number, call the Department of Health where you live.
- Talk with a mediation (mee-dee-EH'-shen) service. Mediators are people who try to settle arguments between different sides. Most cities, counties, and states have mediation services.

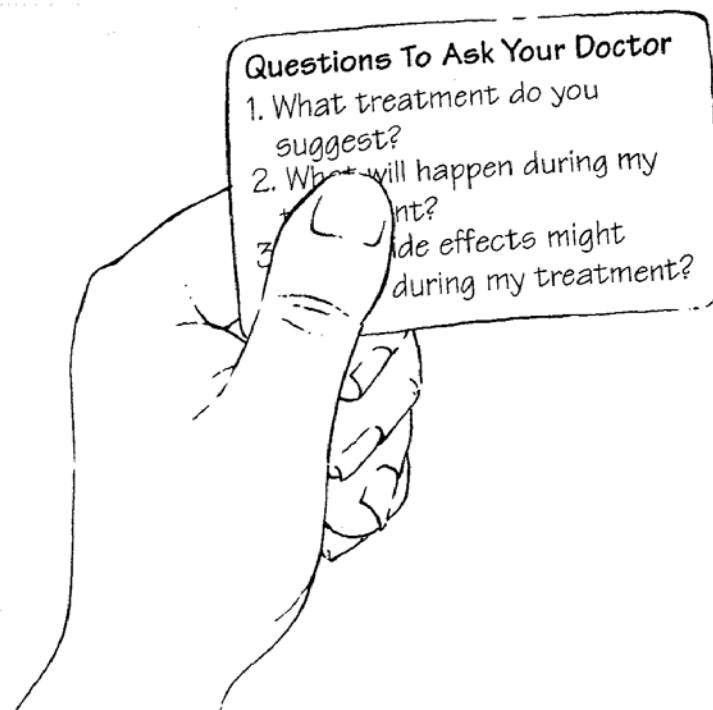


- Call the Protection and Advocacy Service or Legal Rights Service in your state. These services support the rights of people with disabilities.
- Talk to the elected officials [politicians (pol-ih-TISH'-enz)] in your city, state, or province. These people were voted into office to help people like you. They might be able to help you if your rights are not being respected.

Final Note on Rights

Most people become doctors, nurses, and dentists because they want to *help* other people. Sometimes they forget to tell you everything you need to know about your treatment or medicine. Sometimes they are very busy and in a hurry, so they don't tell you enough about what a medicine is for or what its side effects are. Remember, it is still your *right* to know these things.

Make sure you know everything you need to know before you leave the doctor's office. Be sure to tell the doctor how you feel about the treatment that he or she wants you to take.



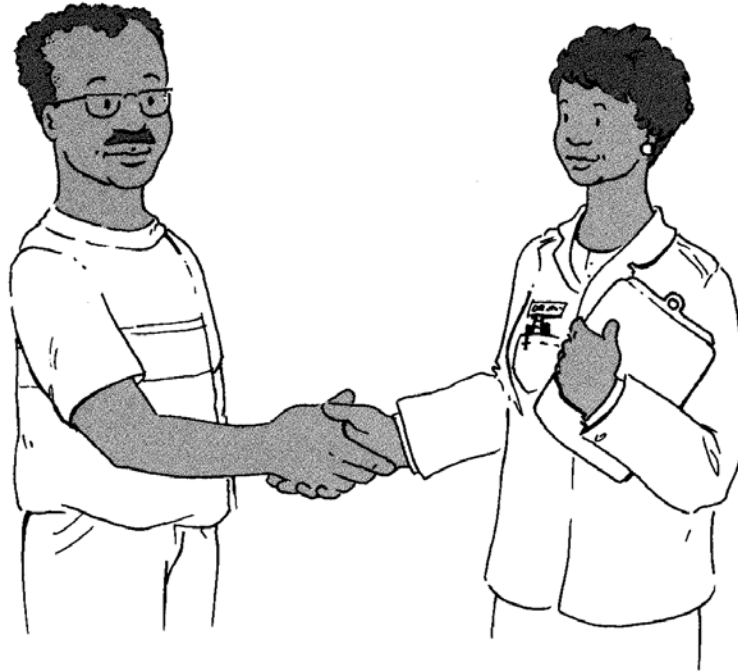
There is a card (go to the end of this book) with a list of questions to ask your doctor. If you look at the card, you will remember to ask your doctor important questions. We added extra cards so that you can share them with your friends.

Now that you know your rights, tell the doctor if you think he or she (or the hospital or clinic) is not following or respecting them. If you are unhappy about your care, talk to all the people involved. Often, the health care person will respect you for sticking up for yourself. If you need to, follow the suggestions (ideas) on how to complain.

Your Responsibilities

It is not only important to know your rights, but also to know your responsibilities (ree-spon-seh-BILL'-it-ees). Remember, responsibilities are the things that you need to do when talking about your health care. You and your doctor should be partners (PART'-nerz) in your treatment. It is in your best interest to be a good patient.

To help your doctor give you the best care possible, you need to do several things. Here are some of them.



1. Talking Honestly

You need to be honest with your doctor. Tell your doctor the truth, even if you feel embarrassed (em-BARE'-esd), uneasy, or shy. If there are other people in the room and you do not want them to know these things, ask the doctor if you can talk to him or her alone. Remember, you have a right to confidentiality (kon-fih-den-chee-AL'-i-tee) when you talk with the doctor. The doctor's questions are important, and he or she needs to know the right answers to give you the best care.

2. Talking About Health Problems

Be sure to tell the doctor about any medicines that you are taking or about health problems or allergies (AL'-er-jees) that you have.

You might want to show the doctor all the medicines that you are taking. Bring them with you when you see the doctor. Sometimes this will give the doctor ideas about any health problems you may have. It will help make sure the doctor does not give you the wrong treatment. For example, your doctor may decide not to give you a new medicine because of a medicine that you are already taking. The two medicines may have bad effects if you take them together.

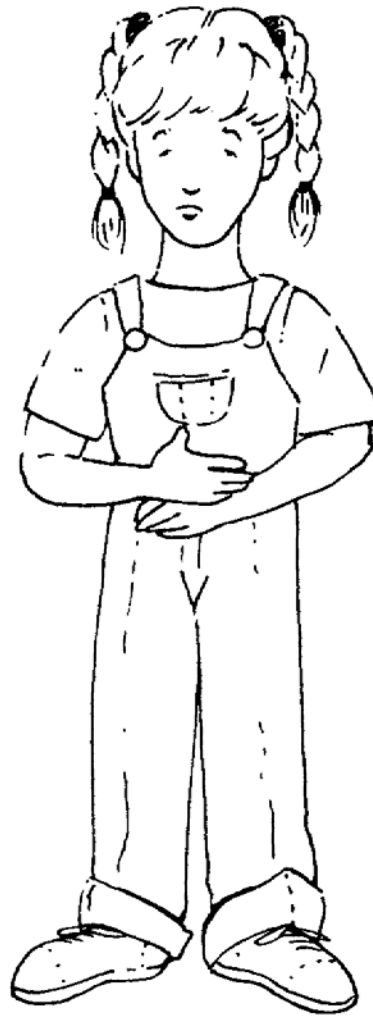
3. Following Directions

Earlier we talked about informed consent and assent (uh-SENT'). Once you agree to a treatment, you should do what the doctor tells you. If the doctor tells you to take medicine, take the medicine *when* the doctor told you to, in the *amount* suggested, and for *as long as* suggested. Some medicines only work if the right amount is taken. Some only work if they are taken for long enough. Some medicines must be taken at certain times of the day. Remember, you agreed to the treatment. Now you have to do your part to help the treatment work.

4. Talking About Problems With Treatment

Be sure to tell your doctor about any problems with your treatment. Sometimes medicines cause *side effects*. Usually, these are changes that you and the doctor do not want to happen.

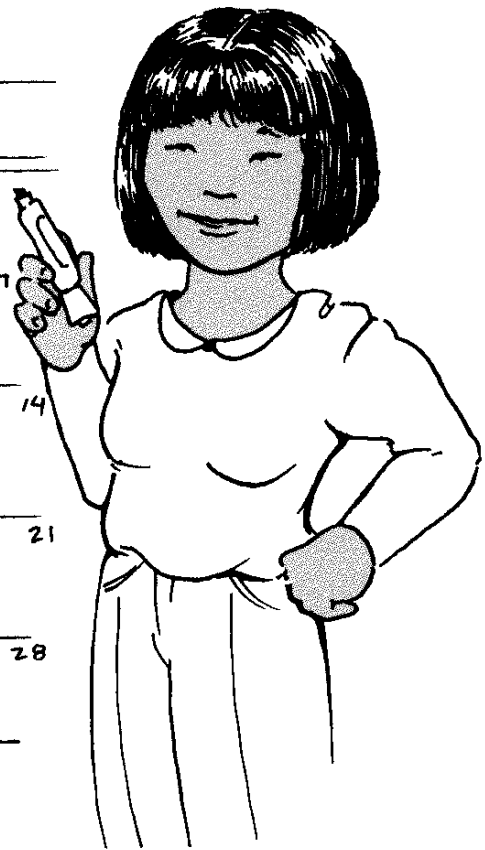
Side effects can be small or big. For example, you might have stomach (STUM'-ik) aches after taking your medicine. If you tell the doctor about this, the doctor may make a change that stops the side effect. The doctor may have you take your medicine with food, or he or she may change the kind of medicine. If you notice bad changes in how you feel after you start taking a medicine, this could be a side effect. Tell someone right away. Tell your doctor, guardian, or care giver. If the medicine is making you feel bad, your doctor may decide to wait and see if the side effects will go away with time, or the doctor may make a change right away. Help the doctor by telling him or her if the treatment is working.



5. Keeping Follow-Up Visits

It is important for you and the doctor to know how well your treatment is working. The doctor might tell you to come back to the office or call the office on a certain day. It is important that you follow these directions. If you have a time set to see your doctor, make sure you stick to it. This will help your doctor decide if you should keep taking your medicine or make a change.

MAY				
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3	4	DOCTOR VISIT	5	6
10	11		12	13
17	18	DOCTOR VISIT	19	20
24	25	26	27	28
31				



Final Note About Responsibilities

Now you know your rights and responsibilities about your health care. It is very important to talk openly with your doctor. When you don't understand something, ask the doctor questions. Do not be afraid to tell the doctor if there is something about the treatment that you do not like. When you agree to a treatment, follow the doctor's directions (de-REK'-shens). Tell the doctor about any changes you feel. The most important thing is that you and the doctor work together as partners. If you do this, you should get good health care.

Go to the end of this book to cut out the Patient Question Cards. You may save the extra ones or give them to your friends.

Thank You

We read these resources for ideas in writing this booklet. We thank these writers for their guidance.

Isaacs, S.L. & Swartz, A.C. (1992). The consumer's legal guide to today's health care: Your medical rights and how to assert them. Boston: Houghton Mifflin.

Schouten, R., & Duckworth, K.S. (1999). Medicolegal and ethical issues in the pharmacologic treatment of children. In J.S. Werry & M.G. Aman (Eds.), Practitioner's guide to psychoactive drugs for children and adolescents (2nd ed, pp. 165-181). New York: Plenum Publishing Corporation.

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About the Series

“Project MED” (Medication **ED**ucation for Consumers) was created with funding from the U.S. Administration on Developmental Disabilities. The goal of Project MED is to provide patients with information, in a manner that they can understand, about the medications that they are taking. The booklets are designed for a broad group of people taking medications: people with mental retardation, autism, reading difficulties, severe mental illness, child and adolescent patients, and people whose first language is not English. By providing this information, we hope to increase each patient’s participation in his or her own health care.

The series consists of eight booklets. The booklets were written to provide basic information about patients’ rights and about medications in easily understood words. There are few medical or legal words, and difficult words are defined.

The eight booklets are:

1. Patients’ Rights and Responsibilities
2. Anticonvulsant Medicines (Medicines for People With Epilepsy)
3. Antipsychotic Medicines
4. Antidepressant Medicines
5. Antimanic Medicines (Medicines for People With Mood Problems)
6. Antianxiety Medicines
7. Stimulant Medicines
8. Other Medicines (Blood Pressure Medicine, Naltrexone, and Over the Counter)

For more information, please contact us:

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