

**YOUR MEDICATIONS –  
WHAT YOU SHOULD KNOW**

A Handbook  
For People With  
Developmental Disabilities



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## INTRODUCTION

Many people take one or more kinds of medication for different reasons. Some medications are for pain or infections (helping to fight off germs); some medications are to control seizures or to help manage behaviors (and make us feel more balanced); and some are to treat specific physical illnesses. Most of the time, the medications we take work well and help us to feel better.



Sometimes medications do not make us feel better and we don't know why or what to do about it. Sometimes we are given medications, but we do not know what they are really for. Sometimes we have been on medications for months and months or years and years and do not know how long we should continue taking them.



We hope this booklet will help you figure out things YOU can do to help you manage your medications and have some control over your own healthcare. If you need someone to help you read it, ask!



## WHAT ARE OUR MEDICATION RIGHTS?

According to the laws of the State of California, people with developmental disabilities have the same legal rights and responsibilities as all other individuals. These rights include things such as a right to privacy, a right to participate in the community, and a right to prompt medical attention. These rights also include “a right to be free from harm, including...excessive medication...” (Welfare and Institutions Code, Section 4502).

“Excessive medication” means that medication should not be used more than necessary or in amounts that might be harmful. It also means that medication cannot be used as a punishment, or for the convenience of residential staff or family members. It also cannot be used as a substitute for other services which might be more helpful than medication (such as a new program, a behavior plan, a fitness and nutrition plan, alternatives to traditional medicine such as herbs or acupuncture, or psychological counseling, etc.)

As an adult over 18 years old, it does not matter whether you live on your own, with your family, in a group home, a nursing facility, a developmental center, or any other type of living arrangement. It also does not matter which type of medication is being used. The law gives you the same rights.

It is also important to understand that you have the right to accept or refuse medication that is prescribed for you or given to you by a care provider. This is called “informed consent”. It means that a doctor must tell you what your choices are to treat your problem along with any risks or side effects, and you have the right to choose which one you want, or to refuse all treatment. You should never do this without discussing it in detail with your doctor first.

## THINGS YOU SHOULD KNOW IF YOU TAKE MEDICATION

An important part of having rights is knowing what to do to get what you need. These are called our “responsibilities”. You have a right to medical care, but you are responsible for taking care of yourself and asking for help if you need it. You have the right to use medications, but you must be responsible by making sure you understand what the medications are for and that you take them properly, following instructions on the medication label as well as those of your doctor.

First, it is useful to understand a few basic facts about medication:

1. Every medication has 2 names. The “**generic**” name is a complicated chemical name. The “**brand**” name is a short, catchy name, often used in advertising. (For example, “diazepam” is the generic name for the brand name “Valium”.)
2. Some medications can be purchased right off the shelf at a drug store or market. These are called “**over-the-counter**” medicines, and include things like aspirin, many cough syrups, or cold medicines. Other medications can only be bought if you have a “**prescription**” from a medical doctor. These medicines must be purchased at a pharmacy because most of them contain stronger chemicals, and some of them require special record-keeping by the pharmacy. Sometimes, you will see “**Rx**”, which is a short form meaning “prescription”.
3. Every medication has a “**dosage**” or “**dose**”. The dosage tells how much of the drug is in each pill, (or spoonful, or other method), and also tells how many pills or spoonfuls, etc. to take. It is very important to take exactly the amount of the medication that it says on the label. Taking too much can cause serious and dangerous side effects, and taking too little may not be enough to provide any benefits.
4. Medicine labels also tell you how often a medicine should be taken, such as “every four hours”, or “once a day at breakfast”, or “at bedtime”. Sometimes a doctor will say to take a medication “**PRN**”, which is a Latin abbreviation that means “as needed”. That means to take the medicine only when you really feel you need it. If you feel you need to

be taking a “PRN” medication very frequently, the doctor should be informed. Following instructions that tell you how often to take it, will ensure that you get the most benefit from your medication.

5. Many medicines come with additional instructions that are just as important as taking the right amount, and taking them at the right time. These instructions include things like “take with food”, “may make you drowsy”, or “do not take with alcohol”. Follow these warnings and instructions carefully!
6. Every drug has possible “**side effects**”. Side effects are unwanted changes (physical or emotional), caused by the drug you are taking. It is important to find out from your doctor what side effects may be expected from any medication you take, and how likely they are for you (since everyone is different).

Some people have minor side effects like a getting a rash, feeling sleepy, gaining weight, having to go to the bathroom more often, having dry mouth, headache, dizziness, and many others. But it is possible that a drug just doesn’t agree with you and your body chemistry, and you could have serious allergic-type reactions that could be life-threatening. Such serious side effects might include: high fever (body temperature), frequent vomiting, stiffness of muscles, seizures, and others. The most important thing is to let your doctor know about any changes to your body right away.

7. Another very important concept to keep in mind when talking about medications is “**drug interactions**”. Drug interactions refers to what happens when different medicines you are taking, mix together in your body. Sometimes, when different drugs mix, the side effects can be so dangerous, that it can cause death. Most of the time this does not happen, because usually doctors prescribe medicines they know work well, and are safe when combined together. If you go to more than one doctor, you should make sure each one knows about all the medicines that you take, in order to prevent dangerous drug interactions.

Another type of drug interaction happens if you are taking different drugs and then stop one or more of them. The new combination of

medications can cause new side effects. That is another reason it is so important to never make medication decisions without talking with your doctor first.

8. Sometimes when we talk about medication, we hear about “**addiction,**” which means that our bodies have become so dependent on the chemicals that we can’t seem to do without it. In some cases, if you try to stop, your body goes through “**withdrawal**” symptoms. These symptoms may include one or more of the following: sweating, rapid heartbeat, panic, anxiety, sleep problems, hallucinations, jerking muscles, dizziness, vomiting, diarrhea, fever, seizures, and others. Keeping in regular contact with your doctor can help prevent these problems, and is part of being responsible in the use of medication. It is important to always ask your doctor if the medication he or she is prescribing can be addictive. You have the right not to take addictive medicine.
9. One of the hardest things about taking medication is remembering to take it! There are many things you can do to help you remember, such as keeping a calendar or reminder list in a handy place, and checking off each time you take your medicine; buying a pill box that has divided sections for each day of the week; or setting an alarm clock or watch to remind you of the right times. If you need more ideas, ask someone to help you.

In order to be safe and to exercise some control over the drugs you are taking, it is a good idea to make a list. This list should include the name of each medication you take, the dosage, how often you take it, and what condition it is for. You should also be sure to list any allergies you have, and any other medical conditions you are being treated for.

If you need to, ask a doctor, family member, friend, or provider to help you make up this list. It could save your life! Don’t forget to update the list any time there are changes to your medications, new ones are added, others are stopped, or dosages are changed. The doctor who changed your medications can help you update your list. Keep a copy of this list in your wallet, and it is a good idea to give a copy to family members, providers, your doctor, and your pharmacist. The list might look something like this:



LIST OF MEDICATIONS

Your Name: \_\_\_\_\_

Your Address: \_\_\_\_\_

Your Phone: \_\_\_\_\_

Any Allergies: \_\_\_\_\_

Your Diagnosis: \_\_\_\_\_

Relative's Name: \_\_\_\_\_

Relative's Phone: \_\_\_\_\_

Generic Name	Brand Name	Dosage	When Taken
1.			
2.			
3.			

## SAFETY CHECKLIST FOR MEDICATIONS

The most important job you have as a consumer who takes medication is to ask questions. Ask the doctor. Ask the pharmacist. Ask your provider. Ask a family member or friend. If you need help, have someone ask for you, and get them to explain it to you and write the answers down for you. Remember, it is your life, your health, and your body, and you have the right to know everything about your healthcare, treatment, and medications.

Sometimes, going to the doctor can feel stressful. This may be because you are not feeling well, or you may not understand all the medical words the doctor uses, or you may feel like you are being rushed. The best way to handle this is to be as well prepared as possible. Think about what questions you want to ask ahead of time. Write them down or speak them into a tape recorder. Bring someone with you who can help ask questions with you. Do not feel bad about asking the doctor to explain something again if you do not understand it the first or second time. That is his or her job! Remember, you are the customer. You also have the right to find another doctor if you are not satisfied.

To help you, here is a list of questions to ask about any medication you are taking. These questions are for your own safety to help you get the most benefit from your medications with the fewest side effects and least risk to your health. You should ask these questions about each medication you take. Once again, be sure to let the doctor and pharmacist know about all medications you take, because some medications should never be taken together.



1. What is the name of my medication?

Brand Name: \_\_\_\_\_

Generic Name: \_\_\_\_\_

2. What is the purpose of the medication?
3. What is the dose?
4. What times should I take this medication?
5. Should I take this medication with food or something to drink?
6. Does it matter if I take it before, during or after a meal?
7. For how long should I continue to take this medication?
8. Are there any special foods, vitamins, herbs, or supplements I should not take while using this medication?
9. Are there other medications I should not take when taking this one?
10. How long will it take for the medicine to start working?
11. Are there any symptoms so serious you would want to know about them immediately?
12. Are there any tests I should complete before starting the medication or while using it?
13. What side effects are common with my medicine?
14. What should I do if I miss a dose?
15. Can any of the other medications I am taking be stopped now?

## ABOUT PSYCHOTROPIC MEDICATIONS

“**Psychotropic medications**” are any drugs used to improve mood, behavior, or mental state, which is interfering with a person’s quality of life.

Psychotropic medications are used most commonly to treat depression, anxiety, manic-depression, schizophrenia, and sleep problems. We have included this special section because: these psychotropic drugs are often prescribed for people with developmental disabilities, they have many side effects, and they need to be monitored more closely.

You might not know if the medication you are taking is considered a psychotropic drug or not. In order for you to be as informed as possible, we are providing a list of only the most common psychotropic medications and what they are most commonly used for, at the back of this booklet. If you recognize your medication on this list, you should read the rest of this section so you are better informed.

If you are taking a psychotropic medication, there are some important guidelines you should know about. This information is for your education and protection. It should not take the place of asking your healthcare professional about any questions you have.

1. When a doctor prescribes psychotropic medications, it is supposed to be the smallest effective amount possible for as short a period of time as possible (unless it is for a problem or disorder that goes on for a long time). As an example, what this means, is that if you were taking psychotropic medication because you were very, very depressed, but have been feeling much better for quite awhile, ask your doctor if perhaps you should take less, or even gradually stop taking it. Do not stop without talking to your doctor first.
2. Your written informed permission must be given before the use of any psychotropic medication. If you take it for a long time, you should be asked to give your permission again at least once per year. If you are not able to, your guardian or conservator should give this permission, but you should be included in any decision. You have a right to have all information about your medication told to you in a way that you can understand. Be sure to bring any communication aids to the doctor with

you. Ask for a written copy of information and consent forms for your records.

3. Any plan for using psychotropic medication should include the dose, how long it should take for the medication to start working (which can take 3 to 8 weeks sometimes), what blood tests or other medical tests should be done while you are on the medication, how long the medication should be continued, what side effects to expect, what risks there are, and an explanation of how the drug will help. It should also include a plan for reducing or stopping the medication, and an explanation of your right to refuse the treatment or to change your mind, and that your consent must be renewed at least once a year.
4. The most common side effects caused by many psychotropic medications are dry mouth, constipation, difficulty urinating, and blurry vision. These do not always happen, and there are many others that sometimes do. There are also some side effects that happen from taking some medications for a very long time, even if you have stopped taking them. It is so important to ask what side effects are normal, and what side effects are dangerous enough to call the doctor.
5. No one is allowed to give you more medication than you need for your condition. Occasionally, there are situations where a staff person or family member gives someone too much of their medication as a way of controlling them or making them easier to live with. Medication should never take the place of good services and programs, and it should improve your quality of life, not interfere with it. Using psychotropic medication excessively, or as a form of punishment, or for someone else's convenience, is **medication abuse**, and should be reported immediately. Telephone numbers to report abuse are listed in the next section of this booklet.
6. Psychotropic medication alone cannot keep someone happy and satisfied. You, the family, friends, and professionals important in your life should be involved in an overall plan to help you live the kind of life you want.
7. Psychotropic medication should only be prescribed by a medical doctor who has seen you and examined you in person. They should never be

prescribed over the phone based on someone's description of a problem. The only exception to this is if more of the same medication is needed. Sometimes, in this case, a "refill" can be authorized by a doctor over the phone, for a limited time. (Sometimes, even a refill cannot be authorized if certain blood tests or other examinations are necessary.)

8. It is usually recommended that a person receiving psychotropic medications should be checked by a doctor at least once every 3 to 6 months, and should be checked after one month if any new medication is started, or after a dose is increased.
9. If you and your doctor decide that you should stop taking a psychotropic medication, usually the best way to do it is slowly. It is usually best to reduce the dose of these medicines over several days or weeks, because stopping a drug too quickly may cause withdrawal-like symptoms. Your body needs time to prepare for the change.

RESOURCES TO HELP YOU IF YOU FEEL YOUR MEDICATION  
RIGHTS ARE BEING VIOLATED

If you are over 18 years old, and live in any type of residential or healthcare facility, and feel you are being abused, with medication, or any other way, call:

Long Term Care Ombudsman

During business hours (8 AM to 5 PM): 800-334-9473

After hours: 800-231-4024

FAX: 310-395-4090

If you are over 18 years old, and live with your family or on your own, and feel you are being abused, with medication, or any other way, call:

Adult Protective Services

During business hours (8 AM to 5 PM): 213-351-5401

After hours: 800-992-1660

FAX: 213-738-6485

For any child under 18 years of age, no matter where he or she lives, if you suspect abuse, with medication, or any other way, call:

Child Protective Services

24 hour crisis line: 800-540-4000

FAX: 213-620-9525

Office of Clients' Rights Advocacy

c/o Protection and Advocacy, Inc.

800-390-7032

916-575-1615

Coordinates advocacy services at each of the 21 regional centers in California

Protection and Advocacy, Inc.

213-427-8747 (Los Angeles office)

Provides free legal advocacy services for people with mental and developmental disabilities

Mental Health Advocacy Services

213-484-1628

Provides free legal advocacy services for people with mental and developmental disabilities

Developmental Disabilities Area Board 10

818-543-4631

State agency that provides advocacy services on behalf of people with developmental disabilities throughout Los Angeles County

For further information about specific medications, call:

U. S. Food and Drug Administration (FDA)

(No charge to dial: 888-INFO-FDA or 888-463-6332)

For referrals to drug and alcohol programs, call InfoLine:

No charge to dial: 800-339-6993 (for all of Los Angeles County)

TDD: 800-660-4026

Your own doctor: \_\_\_\_\_

Phone number: \_\_\_\_\_



## A BRIEF SUMMARY OF SOME OF THE MOST COMMONLY PRESCRIBED PSYCHOTROPIC MEDICATIONS

This list includes many of the most common psychotropic medications. If you do not see yours listed here, it might not be as common, or may usually be used for other purposes, or prescribed for you because of unique circumstances about your situation. Please keep in mind that there are many kinds of depression, anxiety, schizophrenia and other disorders, and each can be treated with several different medications. Only a medical doctor can make the proper diagnosis and prescribe the medication most appropriate to your needs. Do not hesitate to ask questions of your doctor, provider or family member, or ask them to help you find out.

(Brand names, the popular, commercial names for each medication are listed first. The generic name, which is the scientific name, is listed next.)

ANTI-ANXIETY MEDICATIONS - Drugs used to treat feelings of stress, nervousness, panic, extreme worrying, obsessive-compulsive disorder, some phobias (fears), and other stresses. (Also called anxiolytic medicines):

<u>Brand Name</u>	<u>Generic Name</u>
Ativan	lorazepam
BuSpar	bupirone hydrochlorine
Centrax	prazepam
Dalmane	flurazepam hydrochloride
Doral	quazepam
Equanil	meprobamate
Euhypnos	temazepam
Halcion	triazolam
Inderal	propranolol hydrochloride
Librium	chlordiazepoxide hydrochloride
Miltown	meprobamate
Mogadan	nitrazepam
Paxipam	halazepam
ProSom	estazolam
Restoril	temazepam
Serapax	oxazepam
Serax	oxazepam

## ANTI-ANXIETY MEDICATIONS (continued)

<u>Brand Name</u>	<u>Generic Name</u>
Tranxene	chlorazepate dipotassium
Valium	diazepam
Versed	midazolam hydrochloride
Xanax	alprazolam

## ANTI-DEPRESSANTS - Drugs used if you are depressed (feeling very sad):

<u>Brand Name</u>	<u>Generic Name</u>
Anafranil	clomipramine hydrochloride
Asendin	amoxapine
Aventyl	nortriptyline hydrochloride
Desyrel	trazodone hydrochloride
Doxepin	doxepin hydrochloride
Effexor	venlafaxine hydrochloride
Elavil	amitriptyline
Ludiomil	maprotiline hydrochloride
Luvox	fluvoxamine
Marplan	isocarboxazid
Nardil	phenelzine sulfate
Niamid	nialamide
Norpramin	desipramine hydrochlorate
Pamelor	nortriptyline hydrochloride
Parnate	tranylcypromine sulfate
Paxil	paroxetine hydrochloride
Prozac	fluoxetine hydrochloride
Serzone	nefazodone
Sinequan	doxepin hydrochloride
Surmontil	trimipramine maleate
Tofranil	imipramine hydrochloride
Vivactil	protriptyline hydrochloride
Wellbutrin	bupropion hydrochloride
Zoloft	sertraline hydrochloride

ANTI-MANIC MEDICINES - Used for the treatment of manic behavior (being over-active or excessively enthusiastic) and bi-polar disorder (often called manic-depression):

<u>Brand Name</u>	<u>Generic Name</u>
Cibalith-S	lithium citrate
Eskalith	lithium carbonate
Lithane	lithium carbonate
Lithobid	lithium carbonate

ANTI-PSYCHOTIC MEDICINES - Drugs used if you have psychiatric problems, such as schizophrenia, paranoia, hallucinations, and related disorders:

<u>Brand Name</u>	<u>Generic Name</u>
Clozaril	clozapine
Compazine	prochlorperazine
Haldol	haloperidol
Loxitane	loxapine succinate
Mellaril	thioridazine hydrochloride
Moban	molindone hydrochloride
Navane	thiothixene
Orap	pimozide
Orinase	tolbutamide
Prolixin Decanoate	fluphenazine decanoate
Risperdal	risperidone
Serentil	mesoridazine besylate
Serpasil	reserpine
Sparine	promazine hydrochloride
Stelazine	trifluoperazine hydrochloride
Taractan	chlorprothixene
Thorazine	chlorpromazine hydrochloride
Tindal	acetophenazine
Trilafon	perphenazine
Vesprin	triflupromazine
Zyprexa	olanzapine

SEDATIVES - Used to help someone calm down, relax, or sleep:

<u>Brand Name</u>	<u>Generic Name</u>
Alurate	aprobarbital
Amytal	amobarbital
Aquachloral	chloral hydrate
Imovane	zopiclone
Levoprome	methotrimeprazine
Noctec	chloral hydrate
Seconal	secobarbital
Tuinal	amobarbital

STIMULANTS - medications that increase energy or activity:

<u>Brand Name</u>	<u>Generic Name</u>
Adderall	dextroamphetamine
Benzedrine	amphetamine
Cylert	pemoline
Desoxyn	methamphetamine hydrochloride
Dexedrine	dextroamphetamine sulfate
Plegine	phendimetrazine tartrate
Ritalin	methylphenidate hydrochloride

Additional copies of this booklet may be obtained free of charge by  
contacting:



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email: [ab10@pacbell.net](mailto:ab10@pacbell.net)