

# MAKING A CHOICE



This guide was developed by young people in partnership with adult providers.



This is a guide to provide youth with the information they need to be able to give 'informed consent' when making decisions about treatment with psychotropic medications.



For questions about medications or alternative treatments please reach out to your provider, caseworker, resource parent, or another trusted adult who can assist.

Questions about this guide? Please contact [maineYLAT@gmail.com](mailto:maineYLAT@gmail.com).

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## ACKNOWLEDGMENTS

Since 1998, the State of Maine Department of Health and Human Services (DHHS) has provided invaluable support and partnership to the Youth Leadership Advisory Team (YLAT), aiming to enhance both the short-term experiences and long-term outcomes for all youth in foster care. Leadership within the Office of Child and Family Services (OCFS) has been foundational to YLAT's ongoing success, consistently demonstrating a deep commitment to valuing youth voices and incorporating young people's ideas.

This guide was developed by YLAT members in partnership with adult providers. It was created to provide youth with the information they need in order to make informed decisions about their treatments with psychotropic medication. Youth should always consult about their health with trusted providers and adults, and this document can help prepare them to be active members in the conversations and decisions. This handbook is an updated version that was originally created with a group of young people from the Youth Leadership Advisory Team. A special thank you to YLAT Ambassador, Ali Bissonette, who helped to edit and make additions to this second edition.



# PART I: ABOUT PSYCHOTROPIC MEDICATIONS

Decisions about your mental health treatment are very important. This guide will help you explore the risks and benefits to taking psychotropic medications so you can make an informed decision with your doctor and caregiver.

## OVERVIEW

### WHAT ARE PSYCHOTROPIC MEDICATIONS

Psychotropic medications are prescribed medications that affect the brain and nervous system and can cause changes in mood, thoughts, feelings, or behavior. Psychotropics are used to treat an array of mental health conditions like anxiety, depression, bipolar disorder, schizophrenia, and many other diagnoses.

### MAKING DECISIONS ABOUT TAKING PSYCHOTROPIC MEDICATION

You have the right to know all your treatment and support options so you can make an informed decision. You have a right to not be over medicated, to not be punished for refusal to take medications, and to be made aware of the possible risks that come from taking or refusing to take medication. It's important that you know that psychotropic medication is just one tool that can help you overcome mental health challenges. Other treatment options may include different medications, exercise, diet/nutrition changes, meditation, or counseling. You, your doctor, and your caregiver should discuss all your treatment options and create a plan that works for you.

### POSSIBLE SIDE EFFECTS

- ▶ **COMMON:** drowsiness, dizziness, nausea, constipation, blurred vision, headaches, weight gain, tiredness, changes in blood pressure.
- ▶ **LESS COMMON:** Movement disorders/involuntary movement or tremors; Change in heart rhythm (Cardiotoxicity) ; Emotional blunting (an overflow of emotions) or flattening (no emotions at all); Changes in sexual interest; Metabolic effects like high cholesterol and/or diabetes.

**Psychotropics are not addictive but stopping these medications without your doctor's guidance can be very dangerous,** so you will need to work closely with your doctor on all medication decisions.

# CATEGORIES OF PSYCHOTROPIC MEDICATIONS

CATEGORY	WHAT IS IT USED TO TREAT?	HOW DOES IT WORK?	EXAMPLES
<b>Antiadrenergics</b>	Hypertension; Anxiety; Withdrawal symptoms	Lower heart rate, reduce cardiac contractility, and relax blood vessels.	Clonidine, Guanfacine
<b>Antianxiety (Anxiolytics)</b>	Anxiety	Enhance the calming effects of certain brain chemicals.	Lexapro, Zoloft, Prozac, Effexor XR, Cymbalta, Xanax, Ativan
<b>Antidepressants</b>	Depression; Anxiety	Increase the amount of mood lifting chemicals like serotonin and norepinephrine in your brain.	Prozac, Duloxetine
<b>Antipsychotics</b>	Schizophrenia; Psychosis; Bipolar disorder; Hallucinations; Delusions; Irritability; Aggression	Act like traffic cops on the highway, blocking some of the “traffic” (dopamine messages) to slow things down. This helps restore order and makes the brain less sensitive to the chaotic signals.	Haldol, Abilify, Zyprexa, Seroquel, and Risperdal
<b>Mood Stabilizers</b>	Mood disorders	Help to regulate mood by affecting various neurotransmitter systems in the brain.	Lithium, Valproate
<b>Stimulants</b>	Attention Deficit Hyperactivity Disorder (ADHD)	Help the brain focus thoughts by adjusting its chemistry (just like glasses help some people focus their eyes)	Adderall, Vyvanse, Ritalin, and Concerta

→ Use this [DRUG INTERACTION CHECKER](#) to find potentially harmful drug, food, and alcohol interactions.

# FAQS

## Are all psychotropic medications antipsychotics?

No, antipsychotics are a specific category of psychotropic medication that help with managing psychosis, hallucinations, and delusions. Antipsychotics are primarily used to treat schizophrenia, psychosis, bipolar disorder, aggression, and irritability. Not all psychotropic medications are anti-psychotics.

## What are the other options besides medication that may help me?

There are many other options other than medication that may help you including therapy, physical activity, nutrition, establishing good sleeping patterns, stress management skills (deep breathing, time management), avoiding harmful substances, finding new hobbies/interests.

## Do I get to help decide?

You are the one who chooses if you would like to take a psychotropic medication or not. Your guardian and health care providers can help you.

## Will I get in trouble if I don't take this?

You cannot get in trouble if you refuse medication, but your actions have consequences.

## Who needs to know I'm taking this? (teacher, friends, coach, etc)

The only people who need to know are your caseworker and your caregiver. It is important for your caregiver to know so they can properly help you if you have a side effect to the medication.

## Who else should I tell?

Who you tell is completely up to you, nobody needs to know if you don't want them to know.

## Will this affect my family, friends, or other relationships?

Communicate early with trusted family and friends to minimize negative effects on your relationships. Talk about the potential side effects you are experiencing, let them know it is the medication, not your character, and ask them to share if they notice any significant changes both positive and challenging.

## Who will find out I've taken this medication? Are there potential risks to getting a job, or joining the military if I take this medication?

These medications are put into your juvenile record which means nobody can see these records after you turn 18. The only way these medications could affect joining the military is if you are still actively taking them while trying to join.

## What do I do if I have side effects?

If you are having side effects, reach out to your trusted adult and they will help you get in contact with your medication provider.

## How long will I be on this medication?

That is up to you. No medication needs to be for life.

## How will I know/who will decide when it's time to get off this medication?

You, your medication provider, and case worker can discuss coming off medications. It's ultimately your choice, but it is important to remember that there can be side effects when stopping medications, so it is better to discontinue medication as recommended by your provider.

## What happens if I'm ready to get off them?

If you feel you are ready to come off these medications, go to your trusted adult and express to them you feel you are ready. They can make you an appointment to start the process of getting off the medication.

## What will happen if I stop taking it?

If you stop taking these medications, you may experience side effects. Some of the behaviors and feelings that the medications were treating may return.



## PART II: RESOURCES & TOOLS FOR MAKING A CHOICE

## A LIST OF QUESTIONS TO HELP YOU MAKE A DECISION

What information do YOU want to help you make your decision? Here are some possible questions for discussion. Check each of the questions that you need answered in order to make a decision, then bring them to your doctor, psychiatrist, caregiver, caseworker, or other team members to spark conversation.

- Why am I taking this medication?
- Why do you think this is the right medication for me?
- What are the expected benefits of this medication in my situation?
- How long should I expect to wait to see results?
- How will I know if it's working?
- How will this make me feel?
- What are the specific short-term/long-term side effects of this medication?
- Will it make me tired?
- Will the side effects go away?
- What are the other options I have for medication?
- How does this drug interact with other substances? Marijuana (medical or recreational)?
  - Use this [drug interaction checker](#) to find potentially harmful drug, food, and alcohol interactions.
- Will the medication impact my hunger or interactions with food?
- Does this medication impact weight? Either gaining weight or loss of appetite. What can be done to maintain my weight?
- Do I need blood work? What other kinds of medical tests do I need before during and after treatment?
- What is Tardive Dyskinesia? Will I get it?
- How does this help me reach my personal goals?
- What other questions do you have?

# AN EXPLANATION OF YOUR RIGHTS AND WHAT TO DO WHEN YOU FEEL YOUR RIGHTS HAVE NOT BEEN RESPECTED.

## AN EXCERPT FROM MAINE'S YOUTH BILL OF RIGHTS, SPECIFIC TO MENTAL HEALTH

- ▶ You have the right to have an informed choice in the types of physical, dental and mental health care you receive.
- ▶ You have the right to have a choice and options when a treatment provider is being assigned to them.
- ▶ You have the right to see and understand your treatment plans, be informed about and have a say in treatment decisions being made.
- ▶ You have a right to be informed about medications, medication options and to have a voice in decisions about prescription of medication.
- ▶ You have a right to not be overmedicated, to not be punished for refusal to take medications, and to be made aware of the possible risks that come from refusing to take Medication.
- ▶ You should be able to have visitation with people that are important to you while receiving treatment.
- ▶ You should be able to receive care and services that are fair, respectful, safe, confidential and free from discrimination
- ▶ You have a right to access to your medical records.

## WHAT TO DO WHEN YOU FEEL YOUR RIGHTS HAVE NOT BEEN RESPECTED

If you feel your rights have been violated, you should speak up to your caseworker and say that your rights have been violated, and tell them which one.

If you are still having trouble, you can speak to your caseworker's supervisor, your Guardian ad litem or a trusted adult. Be specific and provide examples.

If you don't have success there, you can contact the Ombudsman's Office. An ombudsman (pronounced om-budz-man) helps people when they have concerns about DHHS's involvement in families' lives. You have the right to call the ombudsman if you have a concern. The ombudsman will try to get more information, notify DHHS of problems and work with people to help fix the problems. Call (866)621-0758 or (207)623-1868, or visit: <https://cwombudsman.org/submit-a-complaint/>

<https://www.maine.gov/dhhs/obh/support-services/rights-and-legal-issues/grievance-process>

## Mental Health Grievance Process for Youth and Adolescents

If you feel your rights have been violated by your mental health provider, information on the grievance process for youth and adolescents receiving mental health services and the form for children's mental health grievances can be found here: [Youth and Adolescent Grievance Process and Form](#)

For help with understanding the grievance process for youth and adolescents receiving mental health services, contact (207) 551-2742.

If your grievance or complaint is concerning a provider of Substance Use Disorder services, please contact the [Division of Licensing and Certification](#).

### Where to get help filing a Grievance?

The Grievance Process can be confusing, but there is help available. There are advocates who can either represent you or provide you with information. Advocates have experience helping people protect their rights. They understand the Rights of Recipients of Mental Health Services and the Grievance Process.

There are several agencies that provide advocacy services and/or information:

#### The Disability Rights Center

160 Capitol Street, #4




Augusta, ME 04330

1-800-452-1948 (v/tty) for clients/families (In state only)

1-207-626-2774 (v/tty)

The Disability Rights Center has advocates at The Riverview Psychiatric Center and the Dorothea Dix Psychiatric Center

## A PLACE TO LIST YOUR SUPPORTS AND THEIR CONTACT INFORMATION.

	 NAME	 PHONE	 EMAIL
Doctor			
Psychiatrist			
Caseworker			
Care Provider			
Case Manager			
Other			

## WHAT ARE YOUR PERSONAL GOALS?

A space to think about your goals and how using psychotropic medications may help or challenge you as you reach for your goals.

What are your goals for the next 3 months?

What are your goals for the next year?

If you could look into a crystal ball and paint the next 5 years what would that look like for you?

## WHAT ARE THE RISKS AND BENEFITS?

An exercise to help you weigh the pros and cons of taking psychotropic medication.

	⊕ PROS/BENEFITS	⊖ CONS/RISKS
If I DO take the medication		
If I DON'T take the medication		

# ABOUT

## CATHERINE CUTLER INSTITUTE

The Catherine Cutler Institute is dedicated to developing innovative, evidence-informed, and practical approaches to pressing health and social challenges. Over 175+ research staff engage in funded research in the following focus areas: Children, Youth and Families; Disability and Aging; Economic and Workforce Development; Environmental and Social Resilience; Justice Policy; and Population Health and Health Policy. Our staff is skilled in a wide range of research and evaluation methodologies and statistical analytic skills. Within the Institute, there are key child welfare initiatives that are grounded in uplifting the voices of individuals with lived experience. At the Institute, we have the unique opportunity to bring together many different voices and perspectives from those who are currently in care, alumni, caseworkers and future caseworkers, resource parents, and birth parents to inform policy, practice, and systems-change strategies.



## YOUTH AND COMMUNITY ENGAGEMENT

The Youth and Community Engagement Team (YCE) is housed within the Catherine Cutler Institute at the University of Southern Maine (USM). As a division of Catherine Cutler, the YCE team works to strengthen communities in Maine so that all people experience health, well-being, and belonging. Since the late 1990s, YCE staff have been working with individuals and communities to leverage their leadership and build their skills, resources, and capacity. Our statewide and nationally recognized initiatives provide opportunities for those who don't typically have a voice in decision-making to be heard, valued, and to have their input incorporated. YCE staff work with individuals and communities to leverage their leadership skills, building their capacity and access to need resources.

