

DECISION AID

FOR ANTIPSYCHOTIC MEDICATIONS

Are you thinking about taking an antipsychotic medication?

Has an antipsychotic medication been recommended to you by a healthcare professional?

Would you like more information to help you make a decision?

This decision aid has been designed to help you decide whether to take an antipsychotic medication as part of your recovery activities.

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WELCOME!

This decision aid is for you if:

- You have recently been advised by a healthcare professional that an antipsychotic medication may help support your personal wellness and recovery goals.
- You have never taken an antipsychotic medication; or
- You just recently started on an antipsychotic medication; or
- You want more information about antipsychotic medications.

This decision aid will help you:

- Learn about psychiatric symptoms you may be experiencing;
- Be aware of some choices for services and supports to help you get better;
- Understand the benefits and risks of antipsychotic medications;
- Make a decision about whether to take an antipsychotic medication.

This decision aid does not cover:

- Alternative approaches to treatment such as herbal products, dietary supplements, traditional or folk practices;
- Other kinds of psychiatric medications;
- Detailed information about each individual antipsychotic medication. (Additional information will be available in other decision aids.)

HOW BEST TO USE THIS DECISION AID

CalMEND has put together this material for your information. It may help you be more prepared in making decisions about your health care. It is not intended to replace or substitute for the medical expertise and advice of your health care provider. We encourage you to discuss any decision about treatment or care with your health care provider. We also encourage you to talk with people who can support you in your decision.

The mention of any product, service, or therapy is not an endorsement by CalMEND.

INTRODUCTION

About Decision Aids and Shared Decision-Making

In mental health, there are often many ways to help people get better or well. This means that each person has choices to make in their individual recovery journey. Research shows that people get the most benefit from treatment when they have taken an active role in making choices about their health careⁱ.

Not everyone wants to participate in the same way all the time—each person has his or her own pace and comfort level. Some people simply want to trust and accept the doctors' advice. Others prefer to have family or friends help them sort through the options. Some want to decide on their own.

Sharing what feels comfortable, asking questions, and talking to your doctor are all part of getting the best out of your health care. Information and support can help you understand what choices are best for you.

This decision aid has been designed to help you think about the information and the steps involved in choosing whether to take an antipsychotic medication. Working through this decision aid may help you talk to your doctor in a more productive way.

Your doctor (or a health care professional) has suggested that you try taking an antipsychotic medication to help you right now. But you may have your own thoughts and questions about this.

STAGE 1: PARTICIPATING IN SHARED DECISION-MAKING

1. What do you think and how do you feel at this point?

А	are you leaning in the direction of:	
	☐ Trying medication right away	
	☐ Thinking about taking medication, aft	ter more information and discussion
	Making your own choices about what	it to do or take
	☐ Not taking medication, but looking at	other choices only
	☐ Not deciding right now, but leaving the	he door open about medication
2. Wł	hat role do you want to have in making this	s decision?
	☐ I want to decide on my own	
	☐ I want to decide on my own, after talking wi member, spouse, partner, friend, counselor	
	☐ I want to have counselor, doctor, etc.) help me with my de	
	☐ I want someone else to decide for me, nam member, spouse, partner, friend, counselor	• •
3. Ho	w much more information do you need and	what kind of information?
A COLOR	No more information—l've got what	at I need
NY.	☐ Basic information so that I can give	ve my consent for medication(s)
La Constitution of the Con	More information about the benefit	its and risks of medications
	☐ More information so I can be sure	what benefits and risks matter to me
	Are you interested in going through this dec	cision aid to help you make a choice
	or be sure about the choice you've made?	and to holp you make a choice
	☐ Yes	□ No
1	If you are not interested now, would you wo	ant to return to this decision aid at a
10	later date?	□ No

STAGE 2: GETTING INFORMATION

1. What do I hope to improve about my life by getting mental health services right now?

Please check all that apply to you!



☐ Feel calmer and less upset



☐ Concentrate better, think more clearly



comfortable with others



☐ Get along better with others



■ More aware and in touch with what may or may not be real



■ Have a healthier appetitie



☐ Get things done, stay on task



☐ Remember Better



☐ Feel more relaxed



☐ Feel more balanced



Sleep better



Not hear voices



☐ Feel better about myself



☐ Not have troubling thoughts or beliefs not accepted by others



☐ Feel happier, less sad



□ Have more energy



☐ Talk and express myself more easily



☐ Feel hopeful and not suicidal

If you've checked one or more of the above, make sure that you discuss these issues with your doctor. If none of the above applies to you, try to put in your own words why you are seeking help, then tell your doctor:

Mental health services, including medications, can help you achieve the goals and fulfill the hopes that you have for your recovery. But your doctor, case worker, and support team need to know what's important to you, so that they can make sure the services and supports fit your situation, needs, and preferences.

This decision aid will help you figure out whether antipsychotic medications might be the right choice for you.

2. What are antipsychotic medications? What symptoms or conditions are these medications used for?

The term "antipsychotic" refers to drugs that are used to help some people with mental health symptoms called "psychosis." This may include experiences such as hearing voices or seeing things (hallucinations), unreal beliefs (delusions,) confusion (disorganized thinking), and feeling hyper (agitation).

Antipsychotic medications are also prescribed for many other symptoms and conditions. For example, they are used to reduce symptoms of "mania," such as feeling very high and excited, having less need for sleep, having racing thoughts, or speaking very fast and making little sense.

When prescribed in the right way, antipsychotic medications can help a person feel calmer, less upset or anxious, sleep better, think more clearly, feel more comfortable around other people, and get along better in daily life.

The United States' Food and Drug Administration (FDA) typically approves medications for specific conditions or disorders. Antipsychotic medications have been approved to help people who have diagnoses such as schizophrenia, bipolar disorder, severe depression, and other conditions.

3. What is psychosis? What are psychotic symptoms?

Psychosis is a condition that can be difficult to explain. It is often used to describe a person who is seen by most other people as having "lost touch with reality".

Psychotic symptoms may include:

- Seeing or hearing things that are not seen or heard by other people (hallucinations)
- Holding unusual beliefs that are not accepted by other people (delusions)
- Thinking and speaking in a confused, unclear, disorganized way (thought disorder)
- Showing emotions in a different or unusual way
- Feeling and acting very hyper (agitation)
- Feeling and acting withdrawn, unmotivated
- Showing changes in personality, appearance, and behavior

Psychosis can be caused by mental and physical illnesses. Sometimes, psychosis results from drug or alcohol abuse. Other times it may be the result of the brain simply not working right. There are many psychiatric disorders that may include the experience of psychosis. They include:

- Bipolar Disorder (also known as Manic-Depression)
- Depression
- Dementia
- Psychosis caused by drugs or alcohol
- Schizophrenia

A person can experience one episode of psychosis, which may or may not come back. This is called a first episode psychosis. Some people with first episode psychosis will go on to have schizophrenia or bipolar disorder, while others will have only one episode. Some of the information in this decision aid specifically refers to first episode psychosis, which is different than multiple episodes of psychosis.

4. What are the choices for services and supports that will help in my recovery journey? Are there benefits and risks with these choices?

Antipsychotic medications are often an important step in helping people with psychosis get better, especially when the symptoms are causing serious problems in daily life. Other psychiatric medications may also be considered, depending on the situation.

But other mental health services and supports can be just as important to help people with psychosis succeed in their recovery. For example, therapy that provides support and education for the person and family members has been shown to help people get better faster and stay well longer. There are also special programs that help keep people with psychotic symptoms from being socially isolated and support their efforts at employment and living a full and satisfying life in the community. These are called **psychosocial interventions**. But such programs don't necessarily reduce symptoms or the need for medicines. Indeed, **most research shows that a combined approach using psychosocial intervention and appropriate medication works bestⁱⁱ.**

Some people with psychosis may prefer not to take medication or get any mental health services. Some people may rely on their own personal and family or cultural ways of coping. Some may choose to use herbs or other kinds of complementary and alternative therapies. However, there isn't much research into these other choices for treatment of psychotic illnesses. If you feel strongly about exploring these other choices, you should talk to your doctor, and get more information (See the list of resources on page 24). It's important that you stay in touch with a doctor or mental health professional, in case the psychotic symptoms get worse, or endanger you in any way.

Whichever choice you choose, the ultimate benefit is for you to recover, to live the life that you want to live, as fully as possible. It's important that you stay in touch with people who support your recovery, to make sure that you stay safe, healthy, and connected to your community.

The table below summarizes the benefits and risks of choices for services and supports, for people with first-episode psychosis.

,	RISKS OF CHOICES FOR SERVICE PEOPLE WITH FIRST-EPISODE	
Choices for Services and Supports	Benefits/Advantages	Risks/Disadvantages
Watchful Waiting (means no active treatment right now, but you and your doctor watch for signs that your symptoms may get worse or cause serious problems)	 No side effects, complications, or costs from treatment Opportunity to clarify diagnosis before treatment Opportunity to get more information before treatment 	 Symptoms may get worse and cause problems in your daily life. Suicide risk is significant in active psychosis. Research suggests that the longer psychosis is left untreated, the greater its impact on your life.
Antipsychotic Medication	 Very good chance of psychotic symptoms going away within the first year of taking antipsychotics. Good chance of keeping psychotic symptoms from coming back Research suggests that early treatment can lead to better outcome 	 Many people with first-episode psychosis are particularly sensitive to the side effects of antipsychotics. Most people with first-episode psychosis have a hard time staying on antipsychotics. Medication alone is not enough to get better or stay well, for some people.
Psychosocial Interventions (may be combined with watchful waiting or with antipsychotic medication)	 Cognitive-behavioral therapy (CBT) may be helpful to individuals with first-episode psychosis, in reducing symptoms, coping with illness, and feeling better about life. Individual supportive counseling may also be helpful. Family interventions in early psychosis may be helpful in reducing relapse and improving outcome. 	 Psychosocial interventions have generally been studied as additions to antipsychotic medications, so it's difficult to evaluate how well they work alone. More research is needed for clearer conclusions. Psychosocial interventions take more time and are not as widely available as medications.

5. What are the advantages of taking an antipsychotic medication? How helpful are these medications?

For most people with first-episode psychosis, antipsychotic medications can be very helpful. Research has shown that for most (about 50 to 90 percent) of people with first-episode psychosis, the symptoms of psychosis lessen or go away within the first year of antipsychotic treatment. This can lead to better safety, outcome, and quality of life.

In addition, once people get better, antipsychotic medications help keep the symptoms from coming back. Among people who have experienced a first episode of psychosis, a number of carefully designed studies show that 40 to 60 percent relapse if they are not on medication during the year after recovery from the first episode^{iv}.

This does not mean that once an antipsychotic medication is started, that you have to keep on taking it forever. Stopping medications is an important decision that you and your doctor must make together. Some people do stop medication successfully and never get psychotic symptoms again. But it is not possible to predict who can do without antipsychotics.

For people with bipolar disorder, the drugs are mainly measured on their ability to "calm" mania symptoms. All the antipsychotics help in this regard, with 40 to 75 percent of people experiencing a decrease in symptoms^v.

For many people with schizophrenia, these drugs can reduce symptoms and improve quality of life, as shown by dozens of studies dating back 40 years. However, about 20 percent of people receive no benefit at all from taking an antipsychotic and 25 to 30 percent get only some benefit^{vi}. This is why medication alone is often not enough; for many, psychosocial interventions together with appropriate medication work best.

There is no way to tell who will not get better from an antipsychotic. And often, it takes trying a few different ones to find just the right one for you, one that works the best, with the fewest side effects.

6. What are the risks in taking antipsychotic medications? What are the unwanted results or side effects of this type of medication? What are my chances of getting these side effects?

A decision to take medication means that you will have to:

- Go to the pharmacy to get the medication;
- Take medication everyday;
- See your doctor regularly;
- Get blood tests or other tests as recommended.

It is difficult to take medication daily, for many reasons. Antipsychotic medications are no exception. If you do find it hard to take an antipsychotic medication, talk to your doctor about why you're not taking it.

Overall, studies indicate that 80 to 90 percent of people who take an antipsychotic will have at least one side effect; most will have more than one. Of those who have any side effects:

- 20 to 30 percent will have a serious or intolerable adverse effect and stop taking the medicine within days, weeks, or a few months.
- 35 to 45 percent will stop taking the medicine within six months; and
- 65 to 80 percent will stop taking the medicine within 12 to 18 months^{vii}. This is because the medicine is not working, not well-tolerated, or because of other personal choices^{viii}.

The antipsychotics are divided into two groups: first-generation (also called typical, or conventional) and second-generation (also called atypical). These two groups are very different in terms of the side effects they can cause. Also, within each group, different medications have different side effects. This is why doctors often recommend that you try at least a few, to find just the right one for you, one that works the best, with the fewest side effects.

People with first-episode schizophrenia are especially sensitive to side effects including changes in metabolism, weight gain, and changes in muscle tone and movements (known as EPS or extrapyramidal side effects)^{ix}. In a one-year study of people with first-episode psychosis on some newer antipsychotics, common side effects include: daytime drowsiness, increased sleep hours, weight gain, and problems

with periods for women^x. Sometimes these side effects are mild, sometimes they are very intense.

All this can sound very scary, but there are many ways to prevent or reduce the chances that side effects will happen to you (see p. 16). This is why you should keep track of any problem and always stay in contact with your doctor.

You should never start or stop a medication on your own. The risks of symptoms getting suddenly worse, or problems from suddenly stopping medications can be dangerous.

The following tables list many, but not all of the side effects of antipsychotic medications. Please talk to your doctor if you have questions or want more information.

SIDE EFFECTS OF ANTIPSYCHOTICS THAT YOU CAN MANAGE TOGETHER WITH YOUR DOCTORXI

These side effects can happen fairly soon (within hours or days) after taking the medication. These can be minor to severe, depending on the specific medication and individual reaction. Let your doctor know and ask what you can do about these.

What you may feel or notice	What you can do
Tired or sleepy, sleeping too much	Ask your doctor about changing medication to bedtime; take a short nap or rest
Trouble falling or staying asleep	Ask your doctor about changing medication to morning or daytime; learn about sleep hygiene and relaxation techniques
Muscles feel stiff, tense, crampy or painful	Exercise, take short walks, stretch muscles, See your doctor
Dry mouth	Drink water, chew on sugarless gum, sour candies
Constipation (mild or occasional)	More water, exercise, fiber in diet
Fast heartbeat or occasional heart pounding	See your doctor. Avoid caffeine
Dizzy or lightheaded when standing or moving quickly	Get up slowly from sitting or lying position. Hold on to something to avoid falls. See your doctor
Feeling more hungry than usual	Watch your appetite; don't overeat; exercise more.

SIDE EFFECTS OF ANTIPSYCHOTICS THAT YOU SHOULD MAKE SURE TO LET YOUR DOCTOR KNOW

These side effects may take longer to show up (weeks, months or years). This can range from minor to severe, depending on the individual reaction and the specific medication. Regular check-ups are needed.

What you may feel or notice	What you can do
Weight gain	Exercise, watch your diet. Ask your doctor about switching to another medication that may not cause as much weight gain. (Higher risk of weight gain with many second-generation antipsychotics)
Sexual problems such as low sex drive, trouble with erections, ejaculation or reaching orgasm	Talk with your doctor
For women who should be having regular periods, periods do not come every month or stop	Talk with your doctor
Milk leakage from the breasts	Talk with your doctor
Muscle movements that you cannot control or stop (Tardive Dyskinesia or TD)	Talk with your doctor. In general, higher risk of TD with first-generation antipsychotics

SERIOUS OR LIFE-THREATENING SIDE EFFECTS OF ANTIPSYCHOTICS

These require medical attention right away. Medication may need to be stopped. As with all the side effects, some are more likely with certain antipsychotics than others.

Side effects (medical terms)	What happens
Metabolic Syndrome (abdominal obesity, high blood pressure, high triglyceride levels, insulin resistance)	Changes in metabolism that can lead to diabetes and higher risk of heart disease and strokes
Acute Dystonia (Severe EPS)	Sudden muscle spasm or cramping, making neck twist, or eyes roll back, or jaws lock up. Some people may have a hard time talking, swallowing, or breathing
Seizures	Sudden, self-limiting disturbance in brain activity, often causing involuntary muscle contractions, and changes in mental state
Stroke	Sudden loss of blood supply to the brain, causing brain function problems
Increased body temperature	Risk of heat stroke
Allergic reaction	Skin rash, trouble breathing
Agranulocytis	Bone marrow does not produce enough white blood cells, increased risk for dangerous infections
Cardiac Arrhthymias	Irregular heartbeat, abnormal EKG
Myocarditis	Swelling of the heart muscle, causing tiredness, shortness of breath, rapid breathing, fever, chest pain, irregular heart beat
Neuroleptic Malignant Syndrome	High fever, stiff muscles, sweating, fast or irregular heart beat, high blood pressure, confusion

7. What can be done to prevent/minimize/manage the side effects?

There are many ways to help prevent or minimize the risks of side effects from antipsychotic medications.

- For many people with first-episode psychosis, lower doses of medications may work.
- People who can't take one medication because of side effects, can often change to a different medication that might be better tolerated.

People react in different ways to medicines; there is no way to tell who will respond best to which medicine, or what dose. The best solution is to work with your doctor to find just the right medication at the right dose for you.

There are also many ways to monitor and manage the side effects of antipsychotics, if they do occur:

- Using other medications to prevent or control the side effects.
- Drawing blood to measure changes in white blood cell counts, blood sugar, cholesterol, and liver function.
- Keeping track of weight changes, waist size, blood pressure, heart rate.
- Keeping track of muscle movements, shakes, or stiffness.

You can work with your doctor to keep track of important changes in your body. Always tell your doctor if you notice any changes or problems from taking medications. You can ask your doctor what you should look out for. There are a number of tools and checklists that can help you and your doctor keep track of side effects from antipsychotic medications.

8. Do I have other health problems/concerns that will affect my decision at this time?

For some people with psychosis, the risk of harming themselves or other people is so great, that they need to take medications right away, regardless of other physical health problems. For others, physical health may be the number one concern.

People who are likely to have problems with diabetes, heart disease, or who are overweight, need to take special care in choosing an antipsychotic, since some medications increase the risk of these conditions more than others^{xii}. The FDA has issued a serious warning for all second-generation antipsychotics regarding the higher risk of high blood sugar and diabetes.

Elderly people also need to take special care in choosing to take antipsychotic medications. The FDA has issued a special warning for all antipsychotics about the increased risk of death when taken by elderly patients with dementia-related psychosis^{xiii}.

If you are pregnant, may get pregnant, or are breastfeeding a baby, you should let your doctor know. The effects of antipsychotic medications on pregnancy and breastfeeding babies are a potential concern^{xiv}.

STAGE 3: BALANCING YOUR BENEFITS AND RISKS

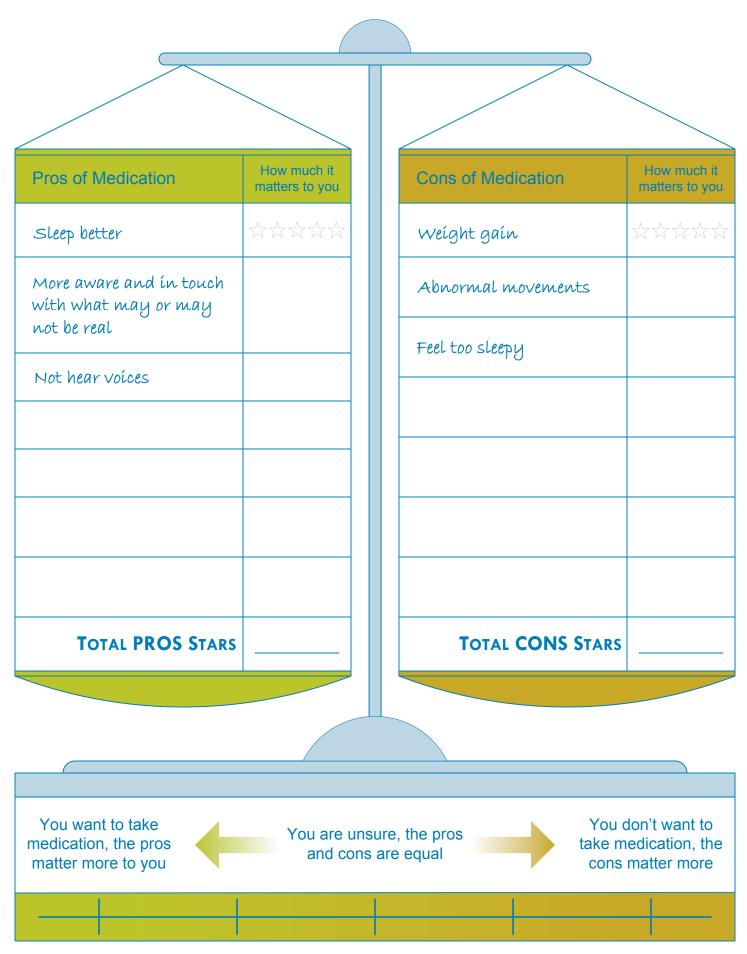
When all is said and done, you (and the friends and family helping you) need to balance the **pros** (i.e., the potential benefits) against the **cons** (i.e. the possible risks) of taking the medication. This will help you make a decision about whether or not taking an antipsychotic medication is the right thing for you to do.

On the following page is a simple decision tool that uses an old-fashioned scale to help you sort things out^{xv}. Here's how to use it:

- 1. The green column on the left has three common pros that people identify. Circle the ones that matter to you.
- 2. Next, think about how much each of the pros you circled matters to you and put one star (*) if it matters a little, more stars if it matters more, and up to five stars (*****) if it matters a lot.
- Now, based on what you have learned about antipsychotic medications, write in and add stars to whatever other pros you may hope for—and put between 1 and 5 stars next to each one.
- 4. Next, move on to the cons listed in the brown column on the right and do the same thing you did for the pros: circle what matters to you, add the stars for what cons matters to you most, write in and add stars for other cons that you may have.
- 5. Lastly, total up the number of pro stars and the number of con stars that you have.

WHERE DID YOU LAND? I	HOW DID THI	NGS BALANCE O	JT FOR YOU?
Total PR	OS stars		
Total CO	NS stars		

BALANCING YOUR BENEFITS AND RISKS IN TAKING ANTIPSYCHOTIC MEDICATION



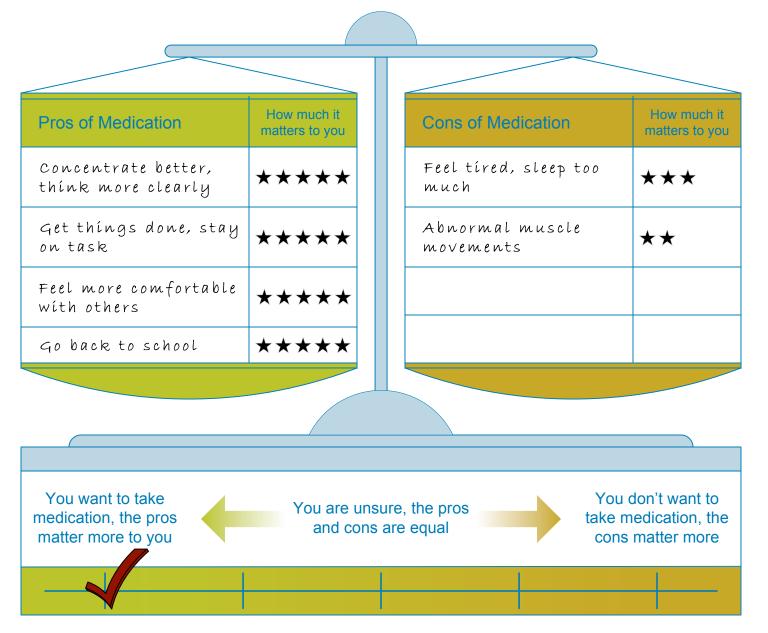
0 0	n you meet.		

What are the experiences of other people in this situation? How have others approached making decisions about whether or not to take medication?

ALBERTO: yes to medication

Alberto had a "nervous breakdown" during his first year at college where he began to feel very hyper and anxious, couldn't sleep at night, couldn't concentrate on his schoolwork and felt like his brain was broken, and was feeling frightened and suspicious of his roommate. He was also hearing voices telling him he was a bad person who deserved to fail at school. Alberto had to leave college and return home. He feels shaky and unsure of himself and doesn't think he can go back to school.

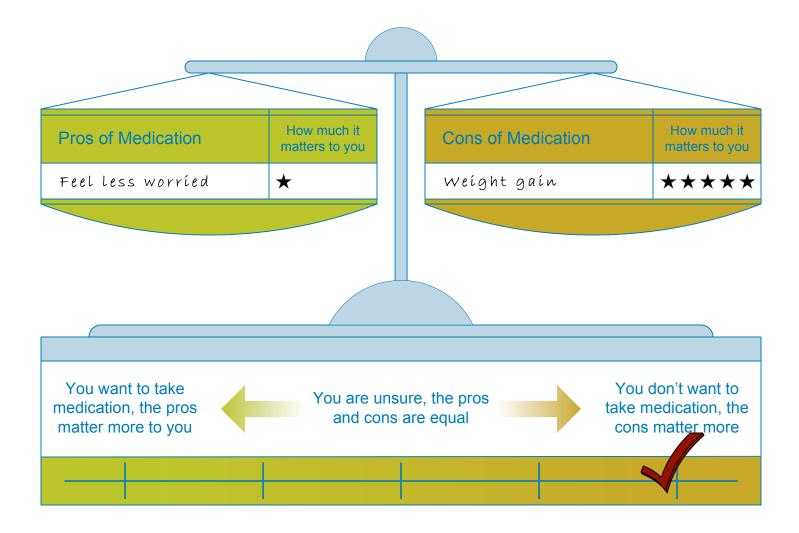
For Alberto and his family, his success in college and a hopeful future are very important. Alberto is a little worried about the side effects of the antipsychotic medication his doctor has recommended, but he is willing to do anything that might help him feel better and be able to go back to school. For Alberto, the potential benefits clearly outweigh any questions or worries he has about trying the medicine.



BETTY: no to medication

Betty, age 27, went to see the psychiatrist because she was having some thoughts and feelings that were making her uncomfortable. Betty felt that her neighbors were spying on her through cameras hidden in her apartment and were giving information to her parents and the police because she was "living in sin" with her fiancé against her family's religious beliefs. She was feeling angry and worried, was withdrawing from her boyfriend and having difficulty with finalizing her wedding plans. Despite these problems, Betty continued to work and was basically doing well, but her co-workers often asked her if she was "OK" and were concerned because she no longer joined them for lunch.

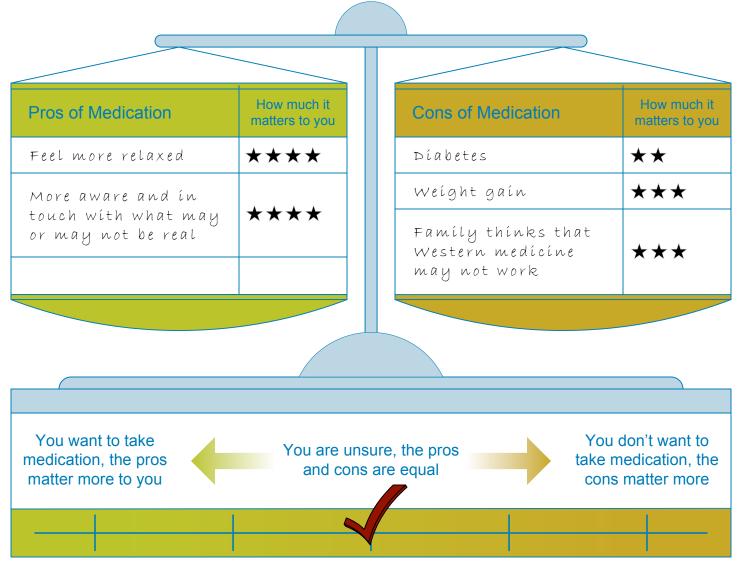
Betty's psychiatrist suggested to Betty that her problems may come from intense emotional conflict about her own needs and desires compared to her family's expectations and traditions. He recommended she come in for brief therapy with a social worker to try and sort things through. He supported Betty in her goal to reconnect with her boyfriend and co-workers. He also encouraged Betty to try taking an antipsychotic medication to help her feel less worried, and decrease her feeling that her neighbors were spying on her. At first, Betty was eager to start treatment. But when she heard that she might gain weight from the medicine and not fit into her wedding gown, she decided to not take medicine and see what kind of help she might get from talking therapy and better community support.



CHANG: watchful waiting

Chang's parents called the police to their home when their 19 year-old son became so angry, violent and threatening that they were worried about their safety. The police took Chang to the hospital and the doctor determined that Chang was "psychotic". His urine test was positive for amphetamines, marijuana and PCP. It's not clear if Chang's problems are the result of a mental illness, his drug use or both. In the emergency room, Chang was given a few shots of antipsychotic medication to reduce his agitation and paranoid feelings. This seemed to help him a lot; his symptoms, though still present, were reduced, and he was ready to go home after spending less than two days in the hospital.

Due to concerns about ongoing safety for Chang and his family, the psychiatrist recommended that Chang start taking an antipsychotic medication to continue to reduce his symptoms, and that he also start a drug abuse treatment program. Chang is 5 foot 7 inches tall and weighs over 250 pounds. His mother has diabetes and she is worried that Chang too will get diabetes if he takes antipsychotic medications. Chang's father has serious doubts about "Western medicine". Chang doesn't want to take any medicine "right now." He believes his problems are a result of hanging out with the wrong crowd and if he could get a job and move away from the area things would be fine. Chang decides to go into a substance abuse treatment program, then go for a check-up with a mental health clinic. He thinks that if he needs to, he will try medication later.



RESOURCES

- Dartmouth-Hitchcock Medical Center, Center for Shared Decision Making http:// www.dhmc.org/webpage.cfm?site_id=2&org_id=108&gsec_id=0&sec_id=0&item_id=2486
- Medline Plus: Health Topics: Psychotic Disorders http://www.nlm.nih.gov/medlineplus/psychoticdisorders.html
- National Alliance on Mental Illness <u>www.nami.org</u>
- National Center for Complementary and Alternative Medicine, National Institutes of Health http://nccam.nih.gov/
- National Institute of Mental Health <u>www.nimh.nih.gov/</u>
- Network of Care for Behavioral Health, Orange County Behavioral Health Services http:// orange.networkofcare.org/mh/home/index.cfm
- Ottawa Health Research Institute: Patient Decision Aids http://decisionaid.ohri.ca/decaids.html
- Rethink United Kingdom mental health membership charity. <u>www.rethink.org</u>
- Schizophrenia.com, non-profit web community
- Wellness Recovery Action Plan, Mary Ellen Copeland. www.mentalhealthrecovery.com/

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- xiv ACOG Practice Bulletin number 92, April 2008 "Use of Psychiatric Medications during Pregnancy and Lactation"
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