BROCHURES

# Optimizing Medication Management for Persons Who Experienced a First Episode of Psychosis

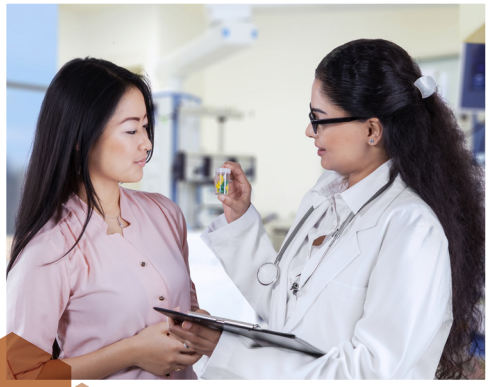
**This document contains 3 brochures that are designed to be used in tandem:**

1. *An Option Grid for Medication Choices for People Who Experienced a First Episode of Psychosis:* A shared-decision-making tool that individuals can use with their psychiatrist or other professionals who prescribe medication (provided via link);
2. *Side Effects of Antipsychotic Medications:* A chart that lists the side effects across a range of first-generation and second-generation anti-psychotic medicines; and
3. *Some Basic Principles for Reducing Mental Health Medicine:* A first-person account of some key lessons-learned when reducing psychotropic medication.

Technical Assistance Material Developed for SAMHSA/CMHS under Contract Reference: HHSS283201200002I/Task Order No. HHSS28342002T

## BACKGROUND ON DEVELOPING THE OPTION GRID AND ASSOCIATED MATERIALS

Option Grids are a type of decision aid that can be utilized by service users and their clinicians in making treatment decisions. They are brief evidence summaries of options in health care decisions that are presented in a user-friendly manner. The document provides a simple structure of rows and columns that are designed to present options and likely outcomes from differing treatment choices. The rows contain questions that are based on common service user concerns. The columns separate the treatment options that are available for the health care decision in question.



The intention behind an Option Grid is to provide a tool that supports people in exploring the options that may be available to them in making health care decisions. Once service users are informed about the possibilities, they will be able to select treatments that best suit their specific, personal needs. Creating a decision aid of this nature requires a process that brings together the most current scientific evidence and filters that data through a team of health care experts. This team, which most often consists of service users, clinicians, and researchers, rigorously synthesizes evidence from systematic reviews and the most reputable clinical guidelines.

Once an Option Grid is constructed, it is put through a series of user tests and is refined until a final version is agreed upon. This document is then used during clinical encounters as a scaffolding of information that prompts a deeper conversation about individuals' specific desires for particular health care decisions. Ultimately, an Option Grid is not meant to simply be a stand-alone summary, but a tool used to promote collaboration and deliberation.

In March 2015, an editorial team was assembled under the leadership of Dr. David Shern and Dr. Robert Drake to address questions about how to manage the use of antipsychotic medications following stabilization from a first episode of psychosis. Along with the Option Grid team at Dartmouth led by Dr. Glyn Elwyn and colleagues Dr. Manish Mishra and Ms. Arianna Blaine, Shern and Drake were joined by Drs. Pat Deegan, Lisa Dixon, Tony Lehman, Julie Kreyenbuhl and Will Torrey. Dixon, Lehman and Kreyenbuhl have a long and distinguished career of research on schizophrenia having conducted the schizophrenia PORT (Patient Outcomes Research Team) studies, as well as Dixon and Kreyenbuhl's involvement in the Recovery After an Initial Schizophrenia Episode (RAISE) initiative. Similarly, Drake, Torrey and Deegan are associated with the Psychiatric Research Center at Dartmouth that has provided national leadership in programming for persons with severe mental illnesses and the use of shared decision making tools. In addition to her doctoral degree in psychology, Pat Deegan is also distinguished by her experience with recovery from schizophrenia and abiding interest in better representing the perspectives of service users in all aspects of care delivery. Dr. Yaara Zisman-Ilani joined the team in the fall of 2015. She is a Rothschild post-doctoral fellow at Dartmouth whose dissertation research involved shared decision making processes for persons with mental illnesses.

The team focused on the often-neglected decision node of what to do with antipsychotic medication management after a person has experienced symptom relief following a first episode psychotic event. The answer most commonly seen is to continue dosing, often

without a thorough re-evaluation of the options that may be considered. This Option Grid is intended to facilitate engagement in the treatment process and to provide support in medication decision making.

After opting to focus on medication decisions after initial stabilization, the team identified a series of frequently asked questions that can typify an informed clinical interaction following stabilization from the first episode. The questions that were ultimately selected are portrayed in the rows of the grid and address various aspects of the three decisions that service users can make following stabilization —

- Continuing on the medication regime that was used in their initial treatment;
- Adjusting their antipsychotic medications and/or adding medication for side effects; or
- Stopping the medication.

**The frequently asked questions include:**

- What is involved with each strategy?
- What are the benefits?
- What are the risks?
- How can I lower the risks? and
- How might this affect my usual activities?

Following the identification of these questions, the research literature was reviewed to determine the most accurate responses to the questions. Systematic reviews, treatment guidelines, meta-analyses, and individual studies were included. Based on this process, draft answers to each of the frequently asked questions were reviewed by the team for accuracy and clarity. An evidence document was subsequently constructed that linked the research literature to each of the statements in the grid or used the consensus of the editorial team when the literature was not informative with regard to a particular assertion.

During the spring and summer of 2016, Dr. Zisman-Ilani conducted a series of semi-structured interviews with persons who had experienced at least one episode of psychosis regarding their opinions of the grid. She sought their first reactions and opinions regarding the purpose of the grid, the degree to which they felt it would be helpful, suggestions for potential additions and deletions for each of the cells in the grid, as well as any additional questions that should be included. Following her synthesis of the interview material, the editorial team revised the grid to address the concerns of the respondents.

The editorial team felt that two adjunctive pieces of information would help service users to better understand the implications of their decisions. Dr. Julie Kreyenbuhl, an expert in pharmacy, constructed a user-friendly description of the likely side effects of commonly used antipsychotic agents. Additionally, Dr. Pat Deegan provided a personal narrative of the process that she undertook in managing her medications as illustrative of the strategies that individuals might employ in maximizing the likelihood of success with their decision. These two pieces, *Side Effects of Antipsychotic Medications* and *Some Basic Principles for Reducing Mental Health Medicine*, appear on the following pages of this document.

To access the most current version of *An Option Grid for Medication Choices for People Who Experienced a First Episode of Psychosis*, please CLICK HERE.

# Side Effects of Antipsychotic Medications

BY JULIE KREYENBUHL, PHARM.D., PH.D.

| Antipsychotic medication | | Side effects comparison | | | | |
|---|---|---|---|---|---|---|
| **Generic name** | **Brand name** | **Sedation** | **Weight gain and metabolic side effects (e.g., increases in blood sugar and cholesterol)** | **Movement side effects** | **Sexual side effects** | **Blurred vision, dry mouth, constipation** |
| Second-generation (* Also available in long-acting injectable formulation) | | | | | | |
| Aripiprazole* | Abilify | Very rare | Rare | Rare | Very rare | Rare |
| Asenapine | Saphris | Common | Uncommon | Rare | Rare | Very rare |
| Clozapine | FazaClo | Very common | Very common | Very rare | Very rare | Very common |
| Iloperidone | Fanapt | Common | Common | Rare | Rare | Very rare |
| Lurasidone | Latuda | Uncommon | Rare | Rare | Rare | Uncommon |
| Olanzapine* | Zyprexa | Common | Very common | Rare | Rare | Common |
| Paliperidone* | Invega | Common | Common | Common | Very common | Rare |
| Quetiapine | Seroquel | Very common | Common | Very rare | Very rare | Uncommon |
| Risperidone* | Risperdal | Common | Common | Common | Very common | Rare |
| Ziprasidone | Geodon | Uncommon | Rare | Rare | Rare | Uncommon |
| First-generation (* Also available in long-acting injectable formulation) | | | | | | |
| Chlorpromazine | Thorazine | Very common | Very common | Uncommon | Uncommon | Common |
| Fluphenazine* | Prolixin | Common | Uncommon | Very common | Common | Uncommon |
| Haloperidol* | Haldol | Common | Uncommon | Very common | Very common | Uncommon |
| Loxapine | Loxitane | Very common | Uncommon | Common | Uncommon | Uncommon |
| Perphenazine | Trilafon | Common | Uncommon | Common | Uncommon | Uncommon |
| Mellaril | Thioridazine | Very common | Very common | Uncommon | Uncommon | Very common |
| Navane | Thiothixene | Common | Uncommon | Very common | Uncommon | Uncommon |
| Stelazine | Trifluoperazine | Common | Uncommon | Very common | Uncommon | Uncommon |

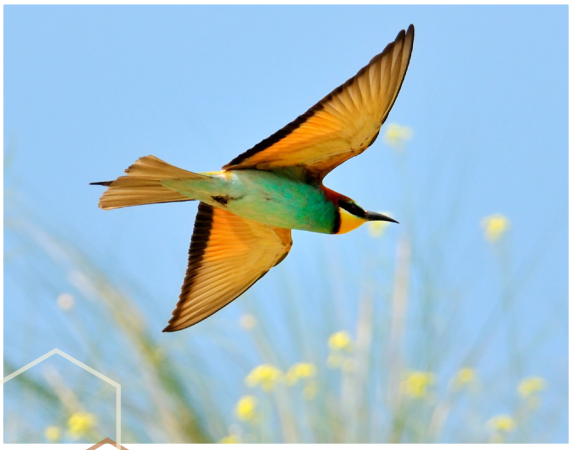
*Very common = almost everyone affected; Common = many people affected; Uncommon = some people affected; Rare = few people affected; Very rare = very few people affected*

# Some Basic Principles for Reducing Mental Health Medicine

**BY PATRICIA DEEGAN, PH.D.**

I was diagnosed with schizophrenia when I was 17 years old. Today I am living a full life in recovery

Over time I learned a lot of important lessons about how to successfully reduce psychiatric medicine without relapsing. Today I use a very small amount of psychiatric medicine. Combined with my powerful Personal Medicine (e.g., my own reserves of strength and hope, my coping skills, and my personal supports), my recovery is strong. Here are some of the lessons I learned about reducing medicine in my recovery:



First, I learned it was better for me to work with my doctor when reducing medications. Together, my doctor and I were able to develop a plan for reducing or eventually discontinuing medicine.

Secondly, I learned my best chance for success was to very slowly reduce one medicine at a time. I found going too fast or reducing all meds at once was a set up for failure. My body and mind needed time to get used to the lower dosages. For instance, many psychiatric medicines dull emotions. As the dose of the medicine was lowered, I began to feel emotions like hurt, anger and sadness again. I had forgotten how intense emotions could be. I needed time to adjust. If I reduced meds too fast, I would have been overwhelmed by the intensity of emotions. Going slow helped me get support from friends as I learned to live a vibrant emotional life again.

I did not use street drugs or alcohol during my medication reduction. Many doctors advise achieving solid sobriety first, before attempting medication reduction. Also, using street drugs or alcohol can cause symptoms to get worse and make reducing medicine even harder.

Like many people, I found it important to drink plenty of water, get exercise and eat healthy food when reducing medicine.

I also found it important to tell a friend about my plan to reduce medicine. In fact, I would ask a close friend to be my “designated observer.” My designated observer agreed to share their impressions of how I was doing as the medication was lowered. Did I seem to

have more energy? Was my sense of humor coming back? Did I seem to be more anxious or suspicious? Of course, I had my own personal observations too. But we can't always see ourselves clearly. Inviting a friend to share their observations was very helpful to me and my doctor. It helped us assess my progress.

Another important strategy was not to attempt a reduction if there was turmoil or a big change going on in my life. Going through a breakup, moving to a new apartment, starting a new school year or a new job – these were NOT the times to reduce medicine because my stress levels were too high. I found it was best to wait for calmer, more settled times to continue my medication reduction.

Finally, I learned that reducing meds does not have to be an all or nothing proposition. I learned it was OK to slow down and even pause dose reductions. There were even times when my doctor and I decided to raise the dose for a while. I learned that raising a dose of medicine was not a failure. I just needed more time to acclimate and get used to lower dosages. I needed more time to build up my Personal Medicine so I had more skills for coping with difficult symptoms and the stresses that life can bring. One helpful way to think of it is that for every dose reduction, I needed time to add more Personal Medicine. In other words, as I was decreasing pill medicine, I was increasing Personal Medicine.

Reducing psychiatric medicine is a journey. It's a time of exploration and learning. It's OK to take our time. It's important to have a plan and support. My advice is don't do it alone.