

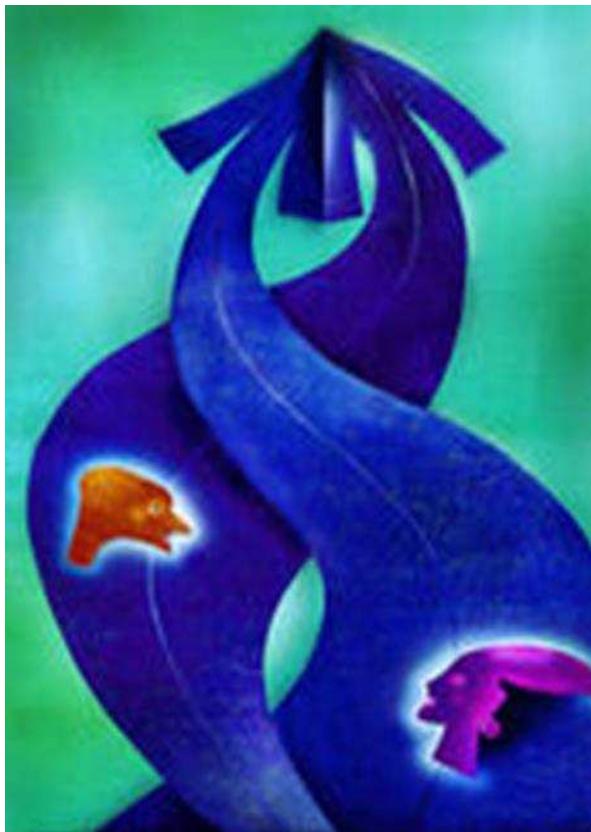
# Lack of Information about Risks and Benefits of Psychiatric Drugs:



*Innovative Ways to Overcome this  
World-Wide Ethical Problem in Psychiatry*

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# Risks and Benefits of Psychiatric Drugs



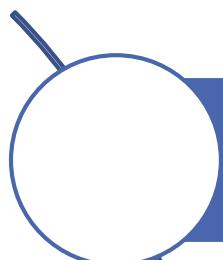
- How much information do people in treatment currently receive, when, and from whom?
- What kind of information do they need, and how can they get it?
- How can reliable information be made widely available to assist decision-making?

# Primary concerns

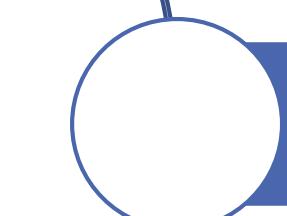
Lack of access to sufficient information to give true **informed consent** to take psychiatric drugs

Lack of access to information about and support for **safe withdrawal** from psychiatric drugs

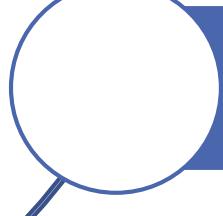
# Psychiatric Medication Discontinuation/Reduction Study: Findings on Informed Consent



78% said they did not have enough information to give informed consent when first prescribed these drugs



Only 21% would begin taking drugs if they could make the decision with their current knowledge



Only 28% said their initial decision to take psychiatric drugs was a free choice

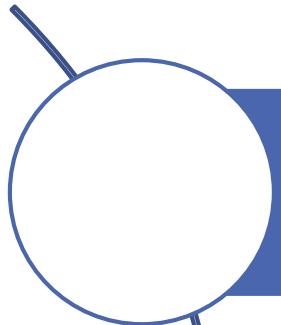
Ostrow, Jessell, Hurd, Darrow & Cohen (2017). Discontinuing Psychiatric Medications: A Survey of Long-Term Users. *Psychiatric Services*, online, July. <https://doi.org/10.1176/appi.ps.201700070>

# Innovative approaches to information needs

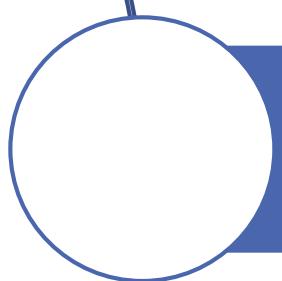
Association of users/survivors in German federal state Rhineland-Palatinate developed independent information sheets on risks and benefits of neuroleptic and anti-depressants, alternatives, withdrawal

US federal project on Shared Decision-Making in Mental Health, created decision support materials, fact sheets on a range of drugs, interactive computer tool for making decisions about neuroleptics

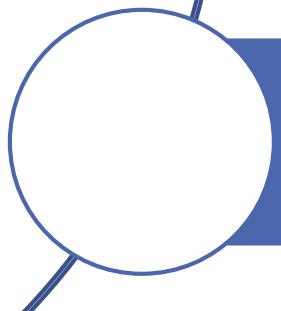
# Rhineland-Palatinate project



Response to local clinic director's refusal to spend time giving patients information on drug effects



Association of users/survivors received grant to create information sheets independent of drug firms' influences



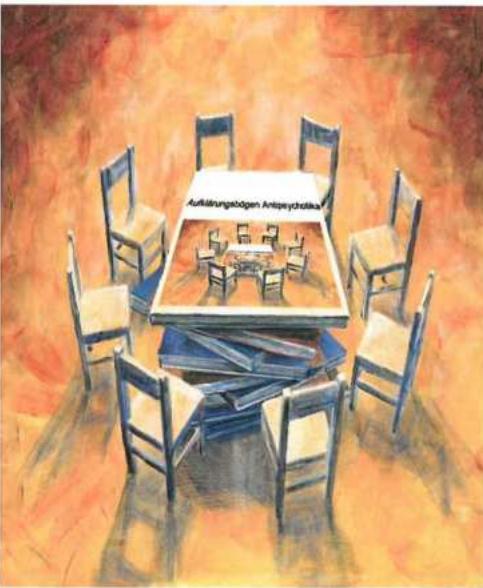
Users/survivors worked with psychiatrists and humanistic anti-psychiatry activist to develop materials over 1 year

[http://www.antipsychiatrieverlag.de/artikel/gesundheit/pdf/lehmann\\_zeitalter-der-aufklaerung.pdf](http://www.antipsychiatrieverlag.de/artikel/gesundheit/pdf/lehmann_zeitalter-der-aufklaerung.pdf)

# Rhineland-Palatinate project



Aufklärungsbögen Antipsychotika



Result: information booklet on neuroleptics and anti-depressants in plain, accessible language

User/survivor group distributed locally; eventually, will distribute across Germany

Given decades of psychiatric patients' marginalization, this is a step towards equality before the law

<http://www.lvpe-ip.de/sites/default/files/pdf/aufklaerungsbogen-nl.pdf>

# Shared Decision Making *in Mental Health*



## Welcome

Shared decision making (SDM) is an emerging best practice in health care and mental health services. It pairs a style of communication and decision making tools to help balance clinical information about mental health conditions and treatment options with an individual's preferences, goals, and cultural values and beliefs.

## Print & Video

**Information on shared decision making topics:** Issue Briefs, Brochure, Tip sheets, and how to videos for administrators, providers, and service users.

**Help:** Quickly learn how to use this interactive tool!

## Decision Aid

A computer-based tool to help you consider the role of antipsychotic medications in your recovery plan.

## Shared Decision Making *in Mental Health*

## Workbooks

**Step-by-step decision support resources:** The workbooks are practical tools that may be copied and used by individuals and families, as well as in peer support and service program activities.

## Cool Tools

**Tip sheets and fillable Worksheets:** Handy, 1-2 page tools that may be copied and used in multiple ways by individuals, families, and peer support and service providers.



# Computer-based decision aid on neuroleptics

U.S. Department of Health & Human Services • Substance Abuse & Mental Health Services Administration  
Center for Mental Health Services

Decision Aid | Shared Decision Making in Mental Health

Home Learn More Glossary Exit

Introduction

## What is Right for Me?

This decision aid is for YOU if:

- your provider has recommended or prescribed an antipsychotic medication.
- you would like to explore some of the benefits and side effects of using antipsychotic medication.
- you want to know more about options for mental health treatment and recovery.
- you are an adult over the age of 18.

Take Charge

- ▶ Your Recovery
- Wellness

Get Information

- Diagnosis
- Medication Options

Create My Report

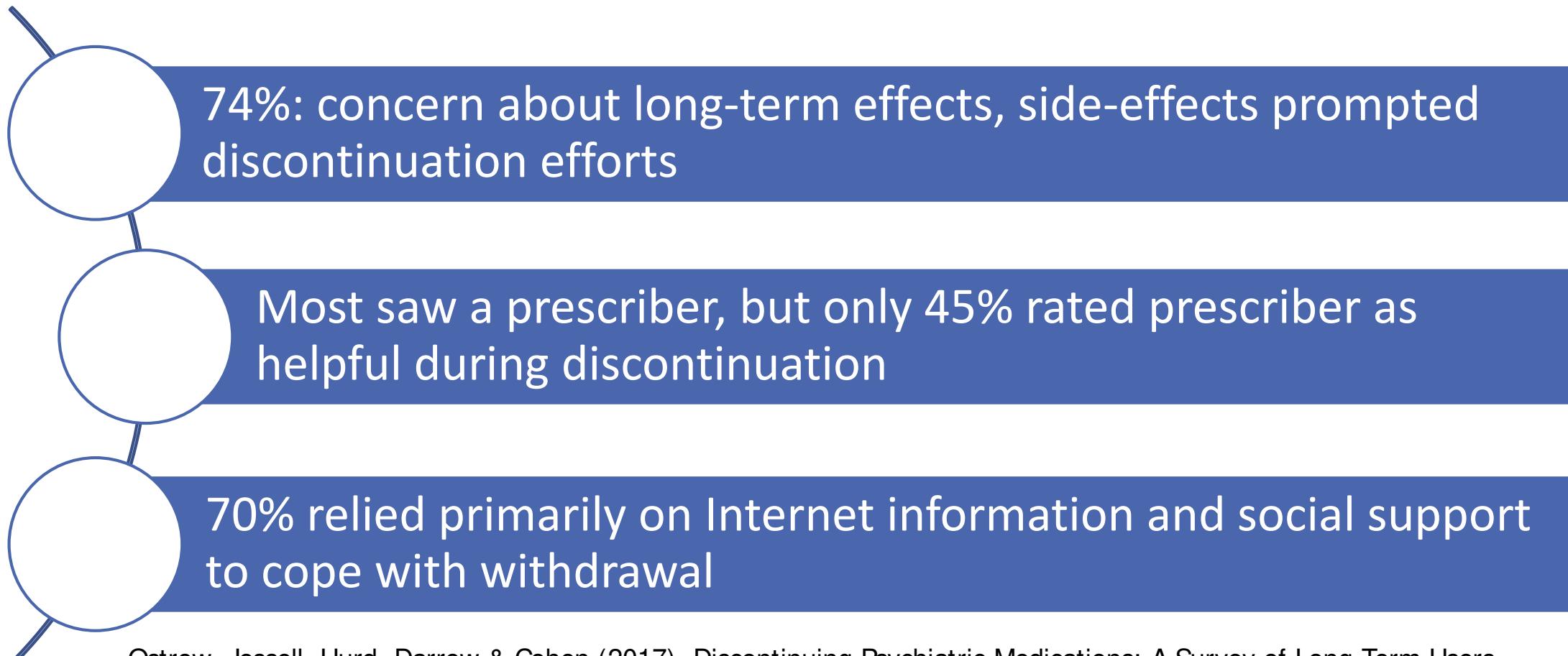
- About Me
- Meds and Me
- Preferences

Next

Page 1 of 7

<http://media.samhsa.gov/consumersurvivor/sdm/StartHere.html>

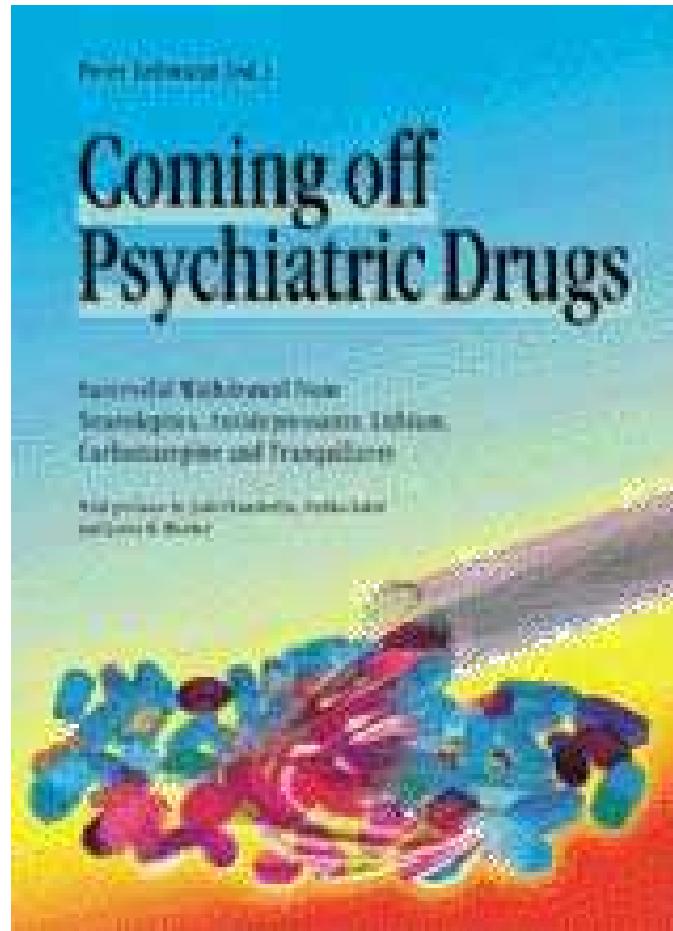
# Psychiatric Medication Discontinuation/Reduction Study: How to Safely Come Off Drugs?



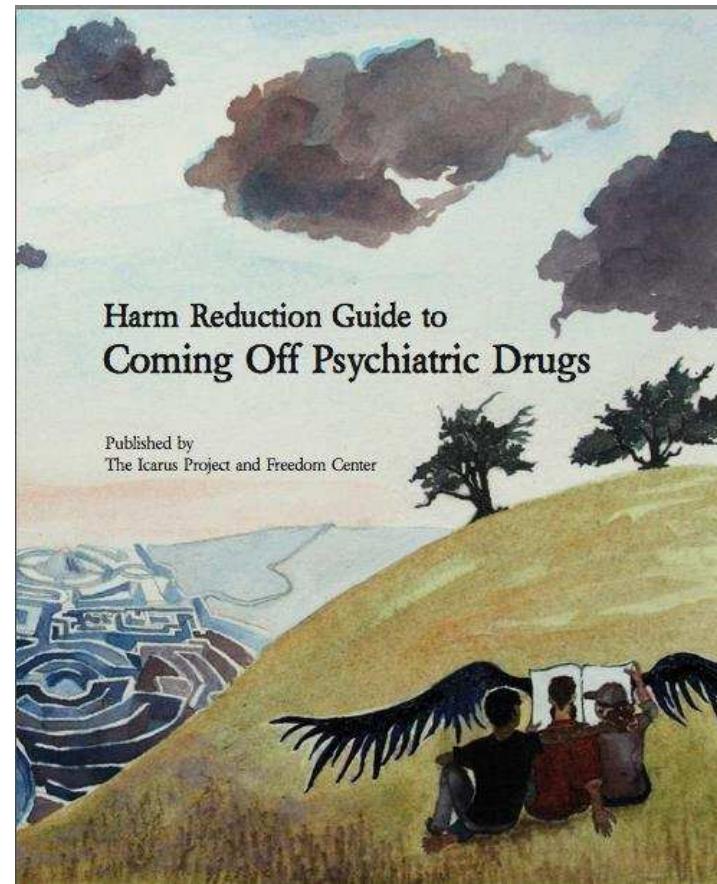
- 74%: concern about long-term effects, side-effects prompted discontinuation efforts
- Most saw a prescriber, but only 45% rated prescriber as helpful during discontinuation
- 70% relied primarily on Internet information and social support to cope with withdrawal

Ostrow, Jessell, Hurd, Darrow & Cohen (2017). Discontinuing Psychiatric Medications: A Survey of Long-Term Users. *Psychiatric Services*, online, July. <https://doi.org/10.1176/appi.ps.201700070>

# User-prepared books for people wanting to withdraw



[http://www.peter-lehmann-  
publishing.com/books1/withdraw.htm](http://www.peter-lehmann-publishing.com/books1/withdraw.htm)



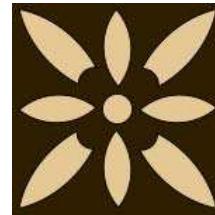
<http://willhall.net/comingoffmeds/>

# Examples of Internet resources for withdrawal



- Podcast series on withdrawing from psychiatric drugs
- Talks by professionals and psychiatric survivors who have come off drugs
- Through website Mad in America, which offers many additional resources on withdrawal

<https://www.madinamerica.com/mia-radio-landing/ltw/>

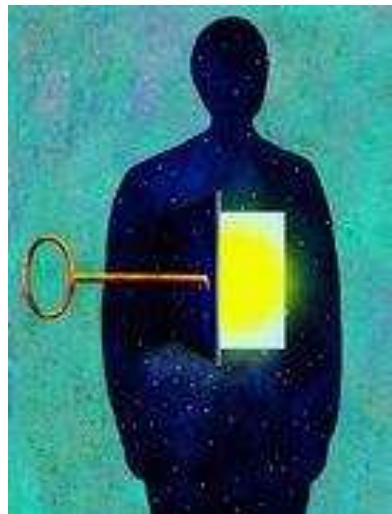


**Everything Matters**  
Beyond Meds

- Monica Cassani's award-winning blog: her journey coming off 6-drug cocktail after 20 years
- A rich source of lists of websites, Facebook groups, and other resources for coming off a wide range of drugs
- Shares both painful and joyous lessons learned through experience

<https://beyondmeds.com/>

# Additional Resources on Psychiatric Drug Withdrawal



Proprietary websites that offer consultations for pay

Websites of individual practitioners; may include advertising

User-run forums about withdrawing from specific drugs

Many informal resources, need to rate quality or effectiveness

# Moving forward

Replicate successful innovative projects

Translate existing resources into many languages

Evaluate, rate, promote and distribute high-quality resources

Research why prescribers fail regarding informed consent

Research why prescribers fail to assist with withdrawal