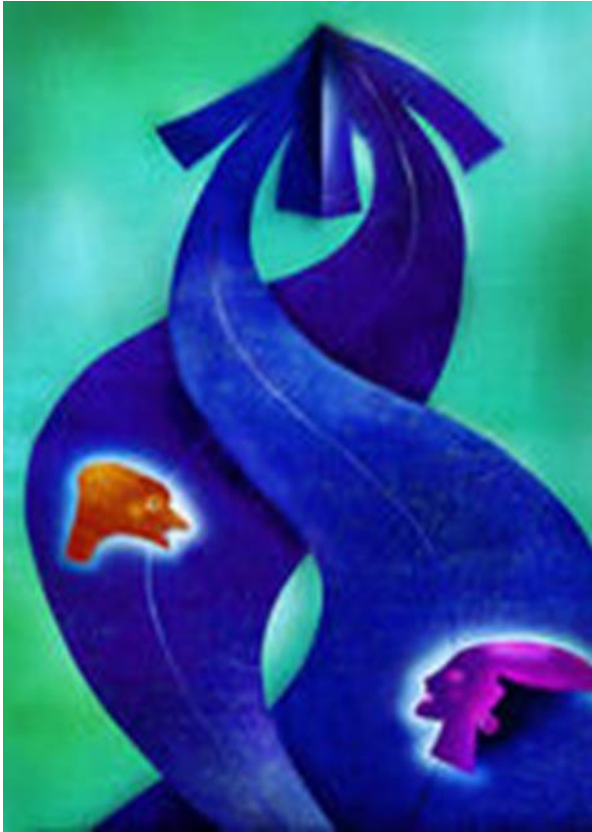


Lack of Information about Risks and Benefits of Psychiatric Drugs:

*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

Rhineland-Palatinate project

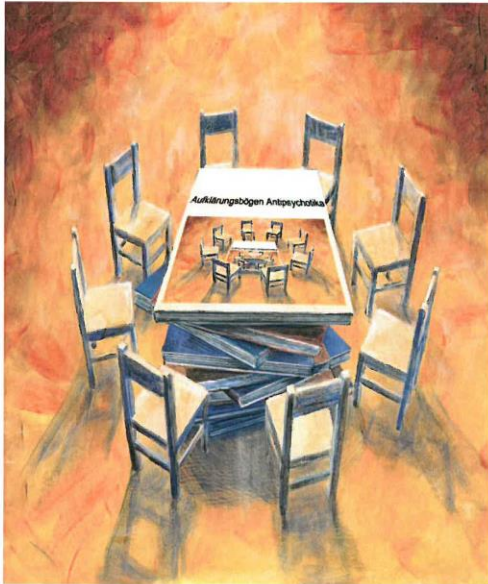
Landes
krankenhaus
RHEIN-MOSEL-FACHKLINIK
ANDERNACH

Landes
krankenhaus
RHEIN-HESSEN-FACHKLINIK
ALZEY

Pfalzkrankenhaus



Aufklärungsbögen Antipsychotika



Result: information booklet on neuroleptics and antidepressants 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-lp.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.

Shared Decision Making
in Mental Health



Print & Video

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

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.

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.

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.



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

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

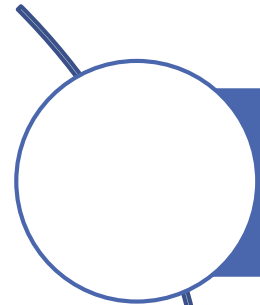
Get Information
Diagnosis
Medication
Options

Create My Report
About Me
Meds and Me
Preferences

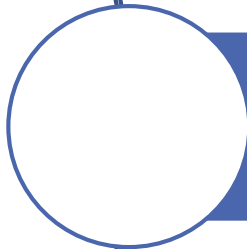
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Page 1 of 7

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

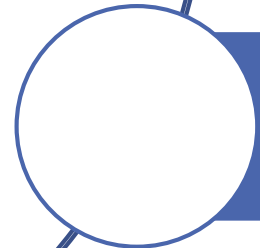
Psychiatric Medication Discontinuation/Reduction Study: How to Safely Come Off Drugs?



74%: concern about long-term effects, side-effects prompted discontinuation efforts



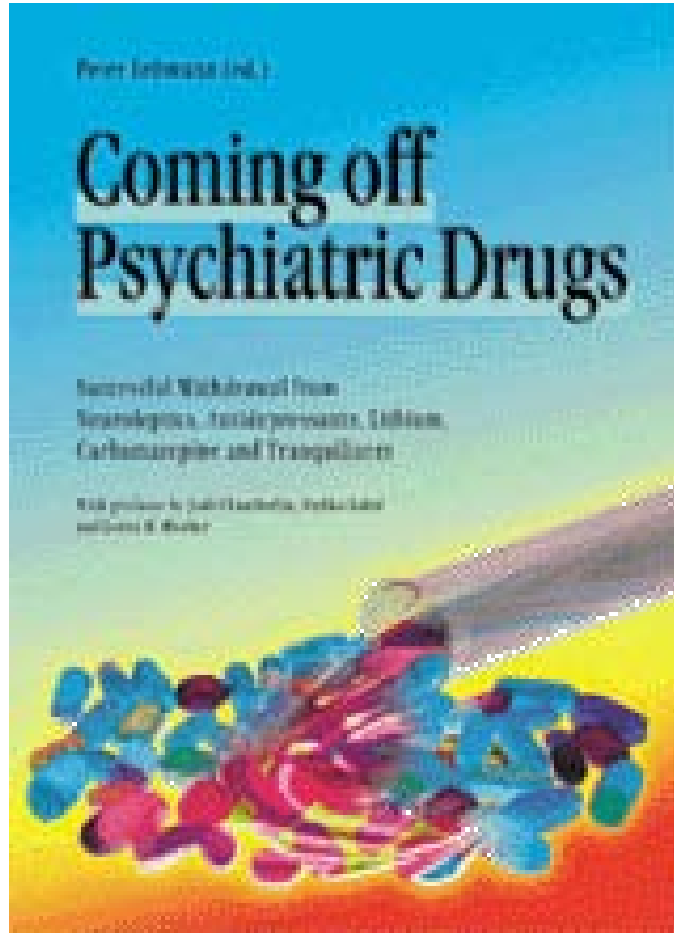
Most saw a prescriber, but only 45% rated prescriber as helpful during discontinuation



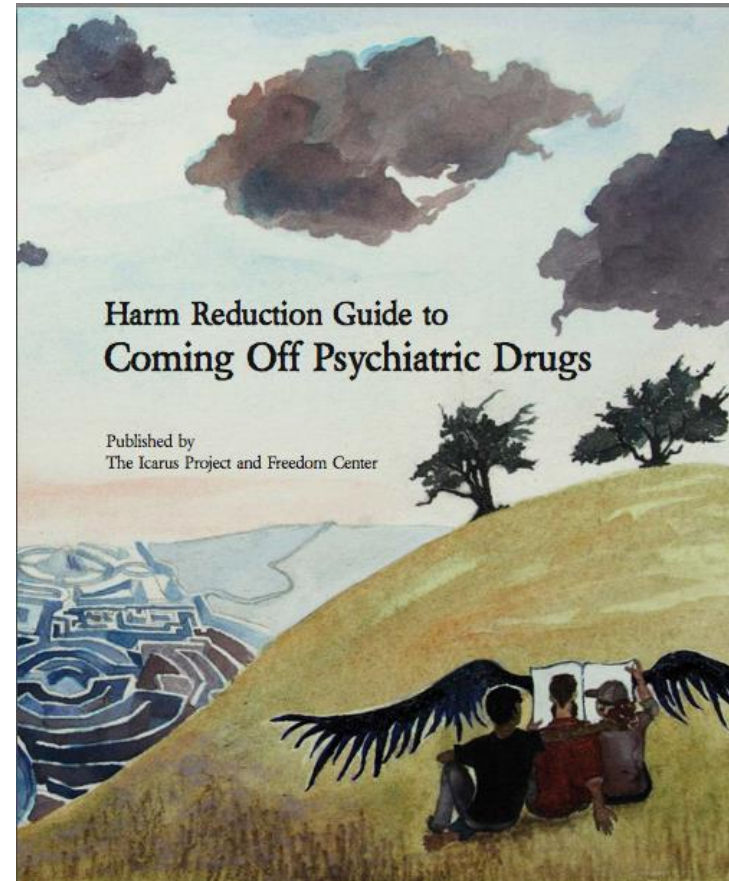
70% relied primarily on Internet information and social support to cope with withdrawal

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://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/>

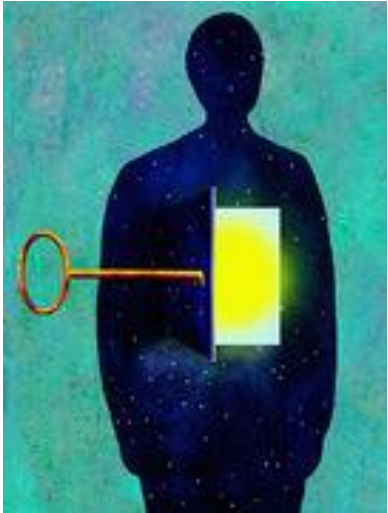


Everything Matters
Beyond Meds

- 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