Prefaces

Much of the conventional wisdom about psychiatric drugs is wrong. Psychiatrists and the pharmaceutical industry have successfully convinced much of the public, through the media, that psychiatric drugs are "safe" and "effective" in "treating" "mental illnesses." Let us look at each of these words in turn:

Safe—generally accepted to mean that they cause no harm, despite many known negative effects such as movement disorders, changes in brain activity, weight gain, restlessness, sudden death from neuroleptic malignant syndrome and many others.

Effective—generally accepted to mean that they reverse or cure the symptoms for which they are prescribed, despite the fact that much research has shown they have a generally sedating effect that masks not only the targeted behavior, but all activities.

Treating—generally accepted to mean that the prescribed agents have specific effects on specific disease processes.

Mental illnesses—generally accepted to mean that there are specific clinical entities known as "schizophrenia," "bi-polar disorder" etc., despite the fact that there are no known structural or chemical changes in the body that can distinguish people who have these so-called illnesses from those who do not.

How is it that these myths have been so successfully accepted as fact? For one thing, those promoting the drugs are authority figures, doctors and scientists who are generally accepted to be presenting value-free experimental results. Another factor, perhaps even more significant, is that those who are given the drugs and who are the ones who have spoken out about their negative effects, are automatically discredited by having been labelled mentally ill. The diagnosis of mental illness carries with it a host of associations, particularly that the person so labelled has impaired judgment and is not a reliable reporter of his or her own experiences.

Nonetheless, it is personal stories which in fact carry enormous weight in the evaluation of the value of these drugs. Reading the eloquent personal testimonials of people who have taken and then discontinued these drugs, some who started with the belief that they were truly lifesaving agents, should be considered along with the positive accounts of researchers and prescribers. In psychiatry, it is the experiences, thoughts and feelings of the patient which are considered to be diseased; therefore, these experiences, thoughts and feelings in response to treatment must be taken into account. Of course, many psychiatrists and other believers in the efficacy of psychiatric drugs can dismiss these accounts by considering them additional "symptoms," but this, of course, is circular reasoning.

The experiences of people who have taken (or continue to take) psychiatric drugs are enormously varied. Some people find them helpful in dealing with troublesome symptoms, and these people, of course, are unlikely to want to discontinue using them. In fact, within this group, many are willing to tolerate troublesome unwanted effects because they find the benefits outweigh the negatives. This group of people is not the subject of this book.

Instead, the book focuses on people who, for a wide variety of reasons, have decided that the drugs are not helpful to them, and who have made the decision to discontinue their use. Such a decision carries enormous consequences, as the treating physician almost always wants the patient to continue and the physician often has enormous powers (such as involuntary commitment) at his or her disposal in order to "persuade" the patient to continue. Indeed, the lack of support a person faces upon a decision to discontinue the use of drugs is often a factor in what is labelled relapse.

As an advocate and activist in the field of mental health and patients' rights (and as a person who discontinued the use of drugs as part of my own personal process of recovery), one of the most common questions I am asked is "how can I discontinue the use of psychiatric drugs?" There is a crying need for information on stopping safely, as well as for supportive structures (such as short-term residential programs and physicians who are willing to consider non-drug approaches) that will enable people who wish to withdraw to do so.

The act of choosing to stop taking psychiatric drugs may be taken for a variety of reasons. Often it is that the negative effects are more troubling than

the original problems, or it may even be that no positive effects are experienced at all (this was certainly my own experience). Unfortunately, the media image of a person who has stopped taking psychiatric drugs is the one that has captured the popular imagination: a person so deluded that he or she is unable to realize that his or her behavior is abnormal and who then usually goes on to commit some horrendous violent crime. Reading about real people and the complex reasons behind their decisions might be a way to counter this negative and destructive image.

It is often said that psychiatric drugs are given to people labelled mentally ill in order that those around them, such as medical personnel and family members, can feel better. Certainly, being around people who are troubled, especially when they are vocal about what is troubling them, can be wearing and difficult. But simply silencing them is not the answer. Instead, we need to listen carefully to the real experiences that people have so that we can learn the true costs of psychiatric drugs on people's lives.

Judi Chamberlin
Co-Chair, World Network of Users and Survivors of Psychiatry, Director of Education and Training, National Empowerment Center
Arlington, Massachusetts, October 30, 2002

This world wide first book about the issue "Successfully coming down from psychiatric drugs," published in Germany in 1998, primarily addresses individuals who want to withdraw based on their *own* decisions. It also addresses their relatives and therapists. Millions of people are taking psychiatric drugs, for example Haldol[1], Prozac[2] or Zyprexa[3]. To them, detailed accounts of

1 Neuroleptic, active ingredient haloperidol, marketed also as Dozic, Haloperidol, Peridol, Serenace

2 Antidepressant, active ingredient fluoxetine, marketed also as Auscap, Deprax, Eufor, Felicium, Fluohexal, Fluox, Fluoxetine, Lovan, Oxactin, Psyquial, Sarafem, Veritina, Zactin

3 Neuroleptic, active ingredient olanzapine

how others came off these substances without once again ending up in the in the doctor's office are of existential interest.

Many of my colleagues in the mental health field spend much of their time developing criteria for the application of psychiatric drugs. Diagnoses like compulsive acts, depression, dermatitis, hyperactivity, hyperemesis gravidarum, insomnia, nocturnal enuresis, psychosis, stuttering, travel sickness etc. can lead to the application of neuroleptics, antidepressants, lithium[1], tranquilizers and other drugs with psychic effects. This development of indications is a responsible task, rich with consequences.

Diagnoses and indications often result in a treatment with psychotropic drugs that can last for a long time. Who can predict whether the drugs—when time arrives—can be withdrawn from easily? From minor tranquilizers, especially the benzodiazepines, we already know the effects of dependency. Withdrawal without therapeutic help and without knowledge about the risks can take a dramatic course. What risks arise from the withdrawal of neuroleptics, antidepressants and lithium.

What factors favor successful withdrawal—successful in the sense that patients do not immediately return to the doctor's exam room, but live free and healthy lives, as all of us would wish? Have we not heard about pharmacogenic withdrawal-problems, receptor-changes, supersensitivity-psychoses, withdrawal-psychoses? Who is able to distinguish relapses from hidden withdrawal problems?

Do we not leave our patients alone with their sorrows and problems, when they—for whatever reasons—decide by themselves to come off their psychotropic drugs? Where can they find support, understanding and good examples, if they turn away from us disappointed (or we from them)?

Peter Lehmann, board-member or the European Network of (ex-)Users and Survivors of Psychiatry and former board-member of Mental Health Europe (the European section of the World Federation for Mental Health), has earned recognition for this difficult task as the first world wide expert to gather experiences from people themselves and their therapists, who have

1 Mood stabilizer, marketed also as Camcolit, Camcolith, Cibalith, Eskalith, Li-Liquid, Liskonum, Lithicarb, Lithium, Lithobid, Lithonathe, Lithotabs, Priadel, Quilonum

withdrawn from psychotropic drugs successfully or who have supported their clients to do so. In this manual 28 people from Australia, Austria, Belgium, Denmark, England, Germany, Hungary, Japan, the Netherlands, New Zealand, Serbia & Montenegro, Sweden, Switzerland and the USA write about their experiences with withdrawal. Additionally, eight psychotherapists, physicians, psychiatrists, social workers, psychologists, natural healers and other professionals report on how they helped their clients withdraw. Via the internationality of the authors the book provides a broad picture of different experiences and knowledge.

The book has a provocative message; life-experiences sometimes differ from scientific agreements. The book is based on the personal experiences of (ex-)users and survivors of psychiatry and the few professionals helping people come off psychiatric drugs. So it is a good place to begin the discussion. The book should be available in each medical practice, in each therapeutic ward, and in each patient's library.

Pirkko Lahti
Executive Director of the Finnish Association for Mental Health and President of the World Federation for Mental Health
Helsinki, August 19, 2002

"There is no tyranny so great as that
which is practiced for the benefit of the victim"—C.S. Lewis

This volume is devoted to a topic that is the subject of a great deal of misguided thinking these days. We live in the era of a "pill for every ill" but too little attention has been devoted to the pills given specifically to affect our psyches. What does it mean to medicate the soul, the self, and the mind? Webster's dictionary defines psyche in all three ways. Are not these chemicals ("psychotropic drugs") interfering with the very essence of humanity? Should not great care and thought be given to this process? If begun, should it not be continuously monitored? Since all three—soul, self and mind—are

at the core of each human being should not he/she determine whether these drugs should be taken based on her/his own subjective experience of them? The answer is, of course, a resounding yes.

Now let's get real. Since there are few objective indicators of the effects of these drugs the patients' own reports are critical. Do the psychiatrists and other physicians prescribing psychotropic drugs listen carefully to each patient's personal experience with a particular one? The answer to the question varies of course but if you speak a different language, are a member of a minority, poor, seen as "very ill" or forcibly incarcerated in a mental hospital the likelihood of being really listened to falls dramatically—although it is not very high for anyone.

Hence, the focus of this book—the stories of persons who were not listened to as they suffered torment of the soul, self and mind from psychotropic drugs—often given against their will, is very important. They are the stories of courageous decisions made against powerful expert doctors (and sometimes families and friends)—and the torment that sometimes ensued. Stopping medications began to restore their brains' physiology to their pre-medication states. Most had never been warned that the drugs would change their brains' physiology (or, worse yet, selectively damage regions of nerve cells in the brain) such that withdrawal reactions would almost certainly occur. Nor were they aware that these withdrawal reactions might be long lasting and might be interpreted as their "getting sick again." They are horror stories of what might happen (but does not have to happen) when attempting to return brains to usual functioning after being awash with "therapeutic" chemicals. Unfortunately, the suffering was usually necessary in order restore soul, self and mind—the essence of humanity.

However, because the drugs were given thoughtlessly, paternalistically and often unnecessarily to fix an unidentifiable "illness" the book is an indictment of physicians. The Hippocratic Oath—to above all do no harm—was regularly disregarded in the rush to "do something." How is it possible to determine whether soul murder might be occurring without reports of patients' experiences with drugs that are aimed directly at the essence of their humanity? Despite their behavior, doctors are only MD's, not MDeity's. They, unlike gods, have to be held accountable for their actions.

This book is a must read for anyone who might consider taking or no longer taking these mind altering legal drugs and perhaps even more so for those able to prescribe them.

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August 26, 2002

The point of departure for this book is the moment at which those who are taking psychiatric drugs—the objects of psychiatric treatment—have already made their own decision to quit or to want to quit. This starting point may be alarming to those readers who look upon the consumers of these substances not as subjects with a capacity for individual decision-making but rather as psychologically unsound and, above all, unable to recognize their own illness (or alternately as consumers of pharmaceuticals from whom they can profit).

Psychiatric drugs are substances which are given to influence the psychic condition and the behavior of their patients. This book refers to the treatment of human beings only. Mentioned are neuroleptics, antidepressants, lithium, carbamazepine[1] and tranquilizers. The withdrawal of drugs used to treat epilepsy in the field of neurology is not a subject of this book.

- Neuroleptics (known also as "major tranquilizers") are so-called antipsychotic drugs, which are administered when physicians (mostly general practitioners, pediatricians or psychiatrists) decide to give a diagnoses such as psychosis, schizophrenia, paranoia, hebephrenia and hysteria. Other possible symptoms that lead doctors to prescribe neuroleptics are those sometimes considered psychosomatic in origin: whooping-cough, asthma,

1 Mood stabilizer, marketed as Atretol, Carbamazepine, Carbatrol, Epitol, Tegretol, Teril, Timonil

stuttering, disturbances of sleep and behavior in children, travel sickness, pruritus (itching) or vegetative dystonia. In the same way that rebellious or aggressive animals of all sorts are given drugs to calm stress-related reactions, so too are elderly disturbed people treated with neuroleptics.

- Antidepressants are given after diagnoses such as reactive, neurotic or brain-organic depression, restlessness, anxiety disorder or obsessive-compulsive disorder, night-anxiety, panic attacks, phobia (e.g. school-anxiety in children), nocturnal enuresis, insomnia and many others. Unhappy animals might receive antidepressants, too, for instance sad dogs, if they are locked up in the house all day while their master is at work.
- Lithium is administered mostly under diagnoses such as mania or schizo-affective disorder.
- The main psychiatric indication for carbamazepine (as well as the chemically-related oxcarbazepine[1] and valproate[2]) is the diagnosis of affective psychosis, especially when the treating psychiatrist has failed to reach the effect he desires with his normal psychiatric drugs. Carbamazepine, valproate and oxcarbazepine which are administered for the treatment of epilepsy in the field of neurology are not subjects of this book.
- Tranquilizers (sometimes called "minor tranquilizers") are substances which are administered after diagnoses such as a lack of motor impulse, depressed mood, phobia, neurosis, panic attack, sleep disorder. Tranquilizers which are administered for the treatment of epilepsy in the field of neurology, are not a subject of this book.

"Authors wanted on the subject: 'withdrawing from psychiatric drugs.'" This was the call for articles I sent out to relevant groups worldwide in 1995:

> "'Coming off Psychiatric Drugs. Successful Withdrawal from Neuroleptics, Antidepressants, Lithium, Carbamazepine and Tranquilizers.' This is the title of a book that will be published in German in 1997/98. A publication in English translation is intended later. We are looking for people who have been prescribed one or several of the above-mentioned psy-

1 Mood stabilizer, marketed as Trileptal

2 Mood stabilizer, marketed as Convulex, Depacon, Depakene, Depakote, Epilim, Sodium Valproate, Valpro, Valproic Acid

> chiatric drugs and who have decided to quit taking them. Of particular interest are positive examples that show that it is possible to stop taking these substances without ending up in the treatment-room of a physician or right back in the madhouse again. For that reason I am looking for authors willing to report—in exchange for royalties—about their own experiences on the route to withdrawal and who now live free from psychiatric drugs. I am also looking for reports from people who have successfully helped others to withdraw from psychiatric drugs in the course of their professional life (e.g. user-controlled support centers, natural healers, homeopaths, social workers, psychologists, pastoral workers, physicians, psychiatrists etc.) or in their personal life (e.g. supporting friends, relatives, self-help-groups etc.)."

I received a series of responses from people who were interested in contributing to this book, including people who had been taking psychiatric drugs as well as some professionals whose articles also appear in this book. One psychiatrist withdrew her offer to contribute, fearing (not without reason) that her practice might be flooded with people wishing to stop taking psychiatric drugs. Because I had received no responses from family members of (ex-)users and survivors of psychiatry, I sent my call for articles to the German "Association for Family Members of the Mentally Ill." The reaction was again silence. Is the reason for this perhaps that those family members who have organized themselves into support groups have been inundated in the past years with free lectures and information from the pharmaceutical industry?

In any case, it would be a mistake to reduce the problem of the prolonged use of psychoactive drugs and the possible complications arising from withdrawal to the fault of disinterested or naïve family members, irresponsible doctors, and the profit-oriented pharmaceutical industry. Two authors who had showed initial interest in contributing their experiences with withdrawal later took back their offer because they had "relapsed." One of them reported that she had mistimed her withdrawal to concur with a breakup. The other informed me that she was in a clinic again because she had experienced another psychosis. Did she experience what those in the field call a "withdrawal psychosis," or was she just overwhelmed with the sudden return of old problems that had yet to be worked through?

Throughout my endeavor to address this subject, I've been cautious enough never to urge others to stop taking psychiatric drugs. I was careful to only approach those who had already quit before I sent out my call for articles. Nonetheless, I wonder if I may have been responsible for leading others to quit in an unconsidered and potentially dangerous way just by having published material on the subject.

Ever since the emergence of psychiatric drugs, many people who have taken prescriptions have made their own decision to quit. One can only speculate how many people have attempted to quit after having been exposed to the idea in an uninformed way only to experience a "relapse" and eventually another prolonged administration of the drugs. I think it is safe to say that a great number of attempts to quit would have been more successful if those wishing to quit and those around them had been better informed as to the potential problems that may arise as well as of means for preventing the often-prophesied relapse. With only a few exceptions, many professionals have little considered how they can support their clients who have decided to withdraw. Responses such as turning their backs on clients and leaving them alone with their problems indicate that professionals have little sense of responsibility regarding this subject.

The many different methods of successfully withdrawing from psychiatric drugs cannot be represented in a single book. As the editor of this book, it was important to me that "my" authors, with the exception of the contributing professionals, openly describe the personal path they took as well as the wishes and fears that accompanied them. They were told that there was only one thing they should not do, namely, to tell others what they should do or to offer surefire prescriptions for how to withdraw. Every reader must be aware of the potential problems and the possibilities, of their own personal strengths and weaknesses, and of their individual limitations and desires such that they can find their own means and their own way of reaching their goal. These reports by individuals who have successfully withdrawn are intended to show that it is possible to reach this goal and to live free of psychiatric drugs.

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Two authors are no longer living: Ilse Gold, who died on September 7, 1998 from breast cancer, which developed after the psychiatric treatment, and Erwin Redig, who quitted his life on June 14, 1999 after repeated violent psychiatric treatment. They had deserved a life of a hundred years.

Peter Lehmann
Berlin, April 14, 2004

Translation from the German by Mary Murphy