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## CHAPTER 8

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# Coming off neuroleptics

PETER LEHMANN

COMING OFF PSYCHIATRIC drugs, especially neuroleptics (also known as anti-psychotics and major tranquillisers), is not an issue for typical psychiatrists, drug companies or family organisations sponsored by drug companies with a vested interest in solving family problems with drugs. They all want to have more, preferably life-long, drug treatment. In many US states there have been court-decisions and law-amendments to permit permanent, often violent, use of neuroleptics in people's communities.

On the other hand, there are more and more reports about the damage caused by neuroleptic use. Many forms of professional action, even within the context of health promotion, might unintentionally enhance the process of marginalisation of recipients of neuroleptics (Lehtinen, Riikonen and Lahtinen, 1997). According to thousands of reports, neuroleptics and other psychiatric treatments can cause a deterioration of health. So it is no accident that the world's biggest organisation of people who have been treatment-objects of psychiatrists has decided to call itself, 'European Network of (ex-) Users and Survivors of Psychiatry'. The term 'survivor' refers to those who have mainly experienced psychiatric diagnosis and treatment as a danger to their health and life. The term 'user' refers to people who have mainly experienced psychiatric diagnosis and treatment as helpful in their specific situation. These definitions are often misunderstood: to survive psychiatry does not mean that psychiatrists are being accused of intentionally killing people; but it does mean that diagnoses such as schizophrenia and psychosis, which very often have a depressing and stigmatising effect leading to resignation and chronic hospitalisation, must be prevented. Drug-effects such as neuroleptic malignant syndrome, tardive dyskinesia, febrile hyperthermia, pneumonia, asphyxia, and other dystonic or epileptic attacks, which can pose a danger to health and sometimes cause death even after small and single doses, have to be survived, in order for people to have a real choice in going on taking neuroleptics or to withdraw. Kerstin Kempker, a German survivor of psychiatry, in her book *Mitgift — Notizen vom Verschwinden* (*Dowry of poison — Notes from disappearing*) shows the indifference of the majority of psychiatric workers to the harm psychiatry

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can do. For example, they elected the German psychiatrist Uwe H. Peters as leader of their professional psychiatric organisation even when he is known to have treated young people with insulin, coma, electroshock, neuroleptics and antidepressants apparently without informed consent (Kempker, 2000).

Liver damage, pigmentation of inner organs, eye and brain damage, chromosome damage, receptor-changes, modification of the personality and 'broken-wing' syndrome are other possible dangerous effects of psychopharmacological treatment. Increased incidence of breast cancer caused by drug-connected increases in the level of the sexual hormone prolactin is discussed in the American Journal of Psychiatry (Halbreich, Shen and Panaro, 1996). But who cares? All these damaging effects are caused by all sorts of neuroleptics; very potent ones, less potent ones, the older typical ones and the newer atypical ones. Differences of damage-causing potential are secondary, for example the most common damage from typical neuroleptics like haloperidol arises from changing the dopamine-D<sub>2</sub>-metabolism, observable as movement-disorders; the most common damage from atypical neuroleptics like clozapine is a change in the metabolism of special subtypes of dopamine-receptors, dopamine-D<sub>1</sub> and -D<sub>4</sub>, seen as producing or increasing psychotic syndromes of organic origin medium and long-term (Chouinard and Jones, 1980; 1982; Ungerstedt and Ljungberg, 1977). Surveys of medical literature on the withdrawal problems of neuroleptics can be found in *Wie Chemie und Strom auf Geist und Psyche wirken (The effects of chemistry and electricity on the human mind and psyche: Lehmann, 1996a, pp. 99ff.)* and *Wie Psychopharmaka den Koerper veraendern (How psychotropic drugs change the body: Lehmann, 1996b, pp. 405ff.)*. There are many good reasons to decide to come off neuroleptics.

### **Withdrawal risks of neuroleptics**

In the USA and Europe there are some remarkable court decisions bringing compensation for drug-damaged people, sometimes with sums of more than one million US\$, on the grounds that there were no attempts made to help people withdraw from the medication over many years. Lacking information about the risk of dependency will soon no longer be a valid defence in these cases, even if psychiatric workers deny vehemently that dependence on neuroleptics occurs. International psychiatric journals are full of reports about massive withdrawal problems from neuroleptics. Physical and psychic withdrawal-symptoms may bring about — in itself unnecessary — continued psychopharmacological treatment (Lehmann, 1996b). The most obvious way to prevent tardive dyskinesia is to limit the use of neuroleptics (Jenner and Marsden, 1983).

The silence concerning withdrawal-symptoms, rebound-effects, supersensitivity-effects, receptor-changes, and tardive psychoses has fatal consequences for users of psychiatry. They cannot act in an appropriate way because they eventually misjudge the problems. Even psychiatric workers have the same difficulties; in withdrawal-studies there is no distinction between true relapse and withdrawal problems (Gilbert, Harris, McAdams and Jeste 1995; Woggon, 1979). There is a lack of scientific rigour, a problem frequently replicated within psychiatric practice. There are, however, many positive experiences of self-determined withdrawal; developing a system to support self-determined withdrawal would enhance the prospects

of (ex-)users and survivors of psychiatry. When individuals have come to their own decision to stop taking psychoactive drugs, it is important that they inform themselves about the many problems that can arise during withdrawal.

Withdrawal symptoms are diseases or problems that were never experienced before treatment with psychoactive drugs or not to such an extent. Knowing exactly what to expect during withdrawal from neuroleptics should enable the person and those who are helping him/her to assess problems realistically and to react appropriately, in order to bring the withdrawal process to a positive outcome. In addition to the usual withdrawal symptoms, another problem often arises: temporary rebound symptoms (sometimes more intense reappearance of the original symptoms present before treatment). The appearance of these somewhat mirror-like rebound symptoms makes it particularly difficult to see the difference between the withdrawal symptoms and the original problems. It should be taken into consideration (as it should be before starting such a treatment) when coming off neuroleptic drugs that hypersensitivity (delirium, withdrawal-related psychoses) is a serious risk. Sleeplessness, mental disturbance, symptoms of the central nervous system, muscular and motor disturbances and troublesome and even lethal disorders of the autonomous nervous system have to be taken into account, leading medical professionals to recommend gradual withdrawal.

There is a significant risk of developing tolerance and becoming dependent on (minor) tranquillisers even after a short period of treatment with a low dose. Severance from tranquillisers can be a dangerous matter with rebound phenomena and powerful, sometimes life-threatening withdrawal symptoms such as convulsions. Other risks are long ongoing depression and suicidal tendencies, anxiety, delirium, and psychoses, which can lead to the risk of continuous or repeated psychiatric drug treatment using progressively stronger and more harmful substances. Withdrawal from neuroleptics (major tranquillisers) is not basically different from withdrawal from other psychoactive drugs, but in addition to the usual withdrawal symptoms (agitation, anxiety, confusion, headaches, lack of concentration, eating and sleeping disorders, increased heartbeat rate, fainting, vomiting, diarrhoea, and sweating) rebound- and hypersensitivity-symptoms can become a problem. This is particularly true for the relatively recent, atypical neuroleptics such as clozapine (Leponex), olanzapine (Zyprexa), remoxipride (Roxiam), risperidone (Risperidal, Rispolin), sertindole (Serdolect), and zotepine (Nipolept).

R. Ekblom of Ullerak Hospital in Uppsala, Sweden, and his colleagues are the authors of a report on supersensitivity psychoses discernible immediately after withdrawal from clozapine. They state that normal relapses are highly unlikely to immediately follow withdrawal. They relate the case of a 23 year-old man who, after being observed to be 'emotionally withdrawn and subject to olfactory hallucinations' was given haloperidol and other neuroleptic drugs. Due to unbearable motor and muscular disturbances which can be the effects of these drugs, they changed to clozapine. 22 months later he developed a dangerous alteration in his blood; the neuroleptic had to be stopped immediately. The psychiatrists recount:

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*Twenty-four hours later his clinical picture changed dramatically. He became tense and restless with intensive auditory hallucinations, hearing voices which ordered him to crawl on the floor and to hit people. He also exhibited persecutory ideas and ambivalence. During his psychotic experiences he was well aware of the fact that he was ill. Thioridazine was given (commercially best known as Mellaril and Melleril, P.L.) in doses of up to 600 mg/day, but his symptoms only gradually diminished and did not disappear. (Ekblom, Eriksson and Lindstroem, 1984, p. 293)*

Uninformed, isolated and therefore defenceless individuals are understandably afraid to be sent back to the hospital and to be forcibly treated with neuroleptics, so they go on taking neuroleptics at the insistence of their psychiatrists or their families.

Rudolf Degkwitz, former President of the German Association for Psychiatry and Neurology, has repeatedly reported on withdrawal symptoms — not publicly, but in specialised journals:

*We now know that it is extremely difficult, if not impossible, for many of the chronic patients to stop neuroleptics because of the unbearable withdrawal-symptoms. (Degkwitz and Luxenburger, 1965, p. 175 [Translation by P.L.]*

George Brooks, psychiatrist at the Waterbury Centre, Vermont, says:

*The severity of the withdrawal symptoms may mislead the clinician into thinking that he is observing a relapse of the patient's mental condition. (Brooks, 1959, p. 932)*

### **How to come off neuroleptics**

Desire, will-power and patience are of extreme importance in coming off psychoactive drugs. The rule of thumb is: do not overdo it, be aware that quick changes in the body's metabolism can cause severe withdrawal symptoms.

We should also be aware that persons coming off psychiatric drugs are weakened, particularly when they have just gone through withdrawal. Even if they are symptom-free, their nervous system is not yet stabilised. Only a person who is completely cured can take on new tasks.

A magic recipe for coming off psychoactive drugs does not exist. It might be that they must be reduced gradually and, if necessary, under medical supervision. Since it is very unusual to come off neuroleptic drugs in a sheltered ward, there are many alternative factors of great importance: contact persons, integration into self-help groups, social relations, access to less harmful substances to help calm severe symptoms (Ochsenknecht, 1993) as well as a disillusioned view of psychiatry. No matter what the conditions of one's life at the time of severance from psychiatric drugs, it is vital to persevere and to gradually pull oneself out of the mire. Others can only support. The decision to live a life free of mind-invading substances must ultimately be the patient's.

A series of articles by people who have freed themselves from dependency

on neuroleptics and very often additional antidepressants, lithium, carbamazepine and (minor) tranquillisers as well as by those who helped these people professionally show that it is possible to stop taking psychoactive drugs without ending up in the treatment-room of a physician or in a psychiatric institution (Lehmann, 1998a). (Ex-)users and survivors of psychiatry who particularly feared the possibility of relapsing into psychiatry have found their own solutions such as autogenic training, social living and working together, examination of the meaning and nature of madness, avoidance of stressful (family) relationships, searching for the sense of life, living closer to nature, swimming, jogging, therapeutic bodywork, yoga, meditation, spiritual practice, prayer, constructive monologues (affirmation) and — this is particularly important — precautionary measures in case of the return of the original psychosocial problems.

There is no patent recipe for excluding problems when coming off or withdrawing psychiatric drugs: the uniqueness of individuals, their problems and their possibilities mitigate against any hope of a generalised approach. The survey of factors described by survivors as being essential for successfully withdrawing illustrates the diversity of strategies and needs<sup>1</sup>.

If any problems are looming, the reduction of doses by degrees is the best way to decrease withdrawal risks. This is especially important if a psychiatric drug has been taken for more than one or two months. Optimally, all the necessary factors for successful withdrawal would be present simultaneously: a responsible attitude, a paced coming off which matches the dose and duration of drug treatment, supportive environments, appropriate assistance, qualified specialists and a supporting self-help group.

But as a rule you can assume that the circumstances while coming off are the opposite of optimal. In the worst cases there is no other possibility than to help oneself get out of the jungle of psychopharmacologic addiction. Ulrich Lindner, a retired theologian, philologist and historian living in the Black Forest, and attempting to withdraw, has been taught how by his brother who has experiences of withdrawal. Gerda W.-Z., writer, translator and publisher of poems and short stories and also living in the Black Forest, encourages:

*We are on our own, called upon to live in a responsible way. We are not only sentenced by others, muzzled by others. We always have more forces (and self-helping forces, too) available than we might have thought in dark days. (Lehmann, 1998a)*

Some argue that as a condition for success it is important to see through the incompetence and the low probability of effective help from medics prescribing psychiatric drugs, to give up illusions about their help and to separate oneself from the doctor or psychiatrist as well as from an understanding of life-problems as illness. 'I gave away 21 valuable years of my life and hoped in vain for an improvement or a cure', says the German

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<sup>1</sup> References to individual experiences of withdrawal are taken from Lehmann, P. (ed.) (1998a) *Psychopharmaka absetzen — Erfolgreiches Absetzen von Neuroleptika, Antidepressiva, Lithium, Carbamazepin und Tranquilizern*. Berlin: Antipsychiatrieverlag. English translation due 2002.

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Bert Goelner, who worked as a type-setter for many years, now in early retirement (disabled); he is also founder of a self-help group for people with compulsive difficulties. Finally he says: 'Notice your harm and be your own therapist — help yourself or nobody helps you' (Lehmann, 1998a).

To make coming off successful in the long term, it is essential to refuse to adapt to unpleasant situations; this can mean leaving a burdensome environment as well as quitting an unsuitable relationship. Getting crazy is a sign showing the necessity of a change, says Maths Jespersen, board-member of the Swedish organisation of (ex-)users and survivors of psychiatry and researcher at the University of Lund (faculty of theatre-science): 'Madness is no illness to be cured. My madness came to call in a new life for me' (Lehmann, 1998a).

Those who learn to take feelings seriously, to follow their instincts and to take notice of and to react to warning signals of a developing crisis escape the danger of psychiatric drugs being prescribed for a second time. Thus developing a calm response to burdensome circumstances in life, patience, courage and determination and the understanding that harm and hurt are inherent to life was helpful for some survivors. Now they admit their mistakes and accept relapses without despairing immediately. So Tara-Rosemarie Reuter, born in the Federal Republic of Germany and having experienced a bipolar perception of herself and the world when she was 40 years old, writes: 'Relapses are needed to refine the instrumentarium. How should we learn if not that way?' (Lehmann, 1998a).

These people have learned to live through fearful situations and to reduce deep-seated anxieties. Wilma Boevink, working as a researcher at the Department of Care and Rehabilitation at the Trimbos-Institute in Utrecht, The Netherlands, reports:

*During the years I developed the courage to face what I tried to cover with all my dependencies. I fought the monsters of my past, and to be able to do this, first I had to admit them and look into their eyes. (...) You have to find the courage to confess to yourself how things went so far.*  
(Lehmann, 1998a)

The sooner (ex-)users and survivors of psychiatry developed an understanding of the connection between violence or abuse and their difficulties, understood mad and troubling symptoms and reacted in alternative ways to crises, the easier it was for them to break off emotional involvement from life problems and deal with them. The hunt that is started after the end of an acute phase — madness or depression — has a preventive character, as the German Regina Bellion, former cleaning-woman, factory-worker, haute-couture sales-woman, teacher, waitress, now living in early retirement, says: 'Who gets down to understanding her psychotic experiences afterwards obviously does not run into the next psychotic phase that soon.' (Lehmann, 1998a)

Some people regard it as a fundamental condition to notice their own (co-)responsibility for their lives, their problem-burdened past and their responsibility for their future (see, for example, Coleman, 1999). Carola Bock, in the former German Democratic Republic working as an industrial accountant, in early retirement since 1991, says self-critically:

*Today I know that I am partly to blame for the states of crisis because I acted wrong and was no angel at all. I often tried to solve my problems in heavy-handed way, and I had not collected enough experience of life either.* (Lehmann, 1998a)

The necessity to take care of healthy and regular sleeping habits is said to be a key component of self-responsibility for some authors. First of all, a sensible and fulfilling occupation — a paid job or a hobby-like activity (especially writing) — as well as love and friendship add to the positive outlook on life which makes it much easier to come off psychiatric drugs (cf: Davey, 1999). Not to lose ground in argument, but to defend oneself and to be able to talk about delicate things is decisive, too. Friendships prove their value if the contact is continued during a crisis.

As long as they make an open non-invasive interchange of personal problems possible, self-help groups are as useful as friendships. Moreover, self-help groups build the scope for mutual advice and for the spread of information about possible damage caused by psychiatric drugs and problems with coming off: 'Most important were the conversations with (ex-)users and survivors of psychiatry who had comparable experiences and a similar attitude towards the world', reports Nada Rath, co-founder of the German national organisation of (ex-)users and survivors of psychiatry. For the English woman Una Parker, retired school teacher and member of Mindlink and ECT Anonymous, co-counselling meant the end of the danger of psychiatric drugs and electroshocks:

*It has made a very great difference to me, and I think that the support I have had from regular co-counselling sessions not only kept me out of the psychiatric system but also helped me be much more effective in my life.* (Lehmann, 1998a)

Homeopathic decontamination, alleviation of withdrawal problems with naturopathic remedies (e.g. Saint John's wort, valerian), body- and psychotherapy, conversations in groups, sports, meditation, praying, shamanic practices and much more can additionally help with reducing problems of coming off and withdrawing.

The importance of a non-discriminating relationship between a person who wants to come off and a professional helper is underlined by Erwin Redig, who spent several years in psychiatry in Belgium and died in 1999 after a forced commitment to a psychiatric hospital:

*This support will not come from the people that declared you ill. This support must be sought amongst people that look upon you with other eyes, that have honest appreciation and true interest.* (Lehmann, 1998a)

Professional helpers note their human presence and their availability in the critical moments of coming off as a prerequisite for effective support. But the (ex-)users and survivors of psychiatry have to do their share in overcoming the problems that can appear when coming off, too. Constanze Meyer, psychologist and psychotherapist, working in private practice as well as a counsellor in a women's centre for substance abuse in Berlin, knows that this is not always easy:

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*These solutions all normally need much time and an active confrontation with the person's own situation, attitudes and patterns of behaviour. (Lehmann, 1998a)*

The more afraid the (ex-)users and survivors of psychiatry are when coming off, the more important becomes the relationship based on trust with the professional helper and, 'the patient knows that he/she can rely on the therapist if there is any trouble' (natural healer Klaus John from Northern Germany). Elke Laskowski, natural healer, indicates the interplay between specialist and human offerings: 'Of course, conversation and offering the patient the opportunity to call at any time have an incomparable therapeutic effect' (Lehmann, 1998a).

Anxieties should be relativised (and in that way reduced) by accurate specialist information about risks of psychiatric drugs and coming off them. It is not very surprising that practices used during the withdrawal process, like acupuncture, are often highly regarded in reports of people who have experiences with psychiatric drugs. Other measures, for example a complete change of diet or a considered use of other drugs, are, because of the frequent problems with getting on well without psychiatric drugs, also worth trying by people who want to come off.

When the body is finally free of psychoactive substances and the system is cleansed, former vitality probably will return. The belief that their stay in psychiatric treatment was just an unfortunate incident which is best forgotten, causes many to push away the thoughts, feelings and behaviours that got them into treatment in the first place.

This can be dangerous. People who were forced into psychiatric treatment should ask themselves how they can change their lives so that the psychosocial problems that led to their psychiatrisation can be diminished.

People who ask their doctors for psychoactive drugs should first ask themselves whether their needs — perhaps a need for peace, relief, attention, understanding, acknowledgement — could not be better taken care of without exposing their body to these risky and dangerous chemicals.

### **Alternatives and measures to encourage withdrawal**

Karl Bach Jensen, the former chair of the European Network of (ex-)Users and Survivors of Psychiatry, developed responsible political demands to enhance the situation of people who made the decision to withdraw from neuroleptics:

*To disagree with the conventional concept of mental illness and the need for synthetic psychoactive drugs — especially when prescribed for long term daily use or even for life — doesn't mean to close your eyes or to deny the real problems many people experience. (Jensen, 1998, p. 343)*

Jensen's point is not that the society shouldn't care at all or that people should be locked up and left alone when they go crazy or out of their mind. A fundamental characteristic of alternative mental health services, he continues, would be to help people to cope with their problems by use of mutual learning processes, advocacy, alternative medicine, proper nutrition, natural healing, spiritual practice, etc. For example, alternative pharmacy



knows a lot about herbs and homeopathic medicine which can help the body and mind to relax and regain its balance. There might not be that much financial profit in these things, but it is the future.

In this field, (ex-)users and survivors of psychiatry could play an important role as staff members and consultants, having the knowledge of what helped them. Such services linked with a positive subcultural identity and dignity could be provided by the public or with public financial support by the (ex-)user/survivor-movement itself giving people the space to meet and create their own lives (see Lindow, 1999). If people are locked up to save their life or to prevent them from doing serious damage to others, nobody should have the right to force upon them any kind of treatment. As a defence against involuntary treatment, Psychiatric Wills or advanced directives — with instructions about the kind of treatment a person wants or doesn't want if it comes to involuntary commitment — should be legally adopted by all states and nations. Alternative systems and decentralised services to meet the needs of people experiencing mental health problems would minimise and in the long run make use of synthetic and toxic psychiatric drugs needless. Until the final abolition of these drugs, a lot of people need help and support to withdraw from them.

An integrated part of building a future ecologically- and humanistically-oriented social system would be the renunciation of toxic substances in nature, the environment, the food chain and in medicine. The renunciation of the deployment of chemical toxins in the psychosocial field could be developed under the following aspects: (Ex-)users and survivors of psychiatry should raise awareness in the public, amongst professionals and consumers, about the inhuman, dangerous and negative cost-benefit outcome of long-term administration of synthetic psychiatric drugs. So (ex-)users and survivors of psychiatry should:

- oppose and fight international recommendations and national laws legitimising forced psychiatric treatment, especially legally-enforced conditions of long-term treatment in the outpatient sector,
- collect and promulgate knowledge about withdrawal problems and how to solve them,
- develop special services and havens for people to overcome dependency on psychiatric drugs,
- ensure that people are informed about the risks of injury and dependency when psychiatric drugs are initially prescribed,
- secure damages for pain and suffering and compensation for disability caused by prescribed psychiatric drugs,
- develop methods, systems, services and institutions for acute, short-term and long-term help and support not depending on the use of synthetic psychiatric drugs at all.

Services mentioned by Jensen are included in the aims of the European Network of (ex-)Users and Survivors (Lehmann, 1998b; Lehmann, 1999). One of these new services is the Berlin Runaway-House, an antipsychiatric project with a long history (Wehde, 1992; Hoelling 1999), whose staff reflect on the risks of psychiatric drugs. This antipsychiatric institution can provide a good shelter to withdraw from neuroleptics too, says Kerstin Kempker, member of the staff of the Berlin runaway-house (see her book *Flucht in die*

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*Wirklichkeit — Das Berliner Weglaufhaus: Escape into reality — The Berlin Runaway-House*; Kempker 1998). When even the World Health Organisation and the European Commission are pleading for the development of innovative mental health policies in consultation with all stakeholders including users, for developing new non-stigmatising and self-help approaches and mental health legislation based on human rights, emphasising freedom of choice (World Health Organization/European Commission, 1999, p. 9f.), optimists may see a chance of providing services (ex-)users and survivors of psychiatry world-wide are waiting for. But even if all these plans are only sentences on worthless paper, people will go on to do what they always did (and what physically ill people do in the exactly same way with prescribed medicine); decide for themselves whether or not to take drugs. Others might guess how high the rate is of true relapse and the rate of withdrawal problems, which are misunderstood as relapses; but it is clear that many withdrawals would have a better outcome if there were knowledge about problems and opportunities to withdraw, more help and less fear, and more knowhow and more positive examples on the side of the users.

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