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MANAGE OR PERISH, OR CHOOSING TO LIVE WITHOUT NEUROLEPTIC DRUGS: DIFFICULTIES AND CHANCES

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Nowadays psychiatrists are discussing if restrictions on so-called care provisions and their excessive regulation may allow for the greatest improvement in the condition of the 'users'. Will the postulated quality of treatment deteriorate if economic factors are given even more weight? Or will that concept, which is called "Managed Care", lead to a discussion of cost-effectiveness and demands for ethics[1] which would diminish the use of ineffective treatment in psychiatry and bring the 'user' into a position to consciously choose among – perhaps – available types of services? Not only psychiatrists should become involved in the processes related to the introduction of "Managed Care". If the 'users' became involved too, they should have a choice of accepting or refusing special psychiatrists' offers of treatment. Having a real choice implies knowing the risks and the possibilities of coming off psychiatric drugs.

Psychiatric workers deny vehemently that dependence on psychotropic drugs (neuroleptics, antidepressants, lithium and carbamazepine) exists. On the other hand, undoubtedly you find physical and psychic withdrawal-symptoms that may cause an – in itself unnecessary – continued psychopharmacological treatment. Many actual forms of professional action, even if they occur in the framework of health promotion, might – unintentionally – enhance marginalization processes, cf. as stated in the "Promotion of Mental Health on the European agenda"[2]. The silence concerning withdrawal-symptoms, rebound-effects, supersensitivity-effects, receptor-changes and tardive psychoses has fatal consequences for 'users' of psychiatry and for their relatives. They cannot act, respectively support, in an adequate 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[3,4], so they are severely lacking in scientific rigor and the same situation is found within psychiatric work. However, there are a lot of positive experiences at self-determined withdrawal; to develop a system to support self-determined withdrawal would enhance the situation of (ex-)users and survivors of psychiatry. The term "user" refers to people who have mainly experienced psychiatric diagnosis and treatment as helpful in their specific situation. The term "survivor" in turn refers to those who have mainly

experienced psychiatric diagnosis and treatment as posing a danger to their health and life. These definitions are often misunderstood: to "survive psychiatry" does not mean that psychiatrists are being accused of trying to intentionally maltreat or kill people; but it does mean that diagnoses such as "schizophrenia" and "psychosis", which very often have a depressing and stigmatizing effect leading to resignation and chronic hospitalisation, must be prevented and that 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 even cause death even after small and single doses, have to be survived, so they could have a real choice to go on taking neuroleptics or to withdraw, eventually with experts' support.

1. WITHDRAWAL-RISKS OF MINOR AND MAJOR TRANQUILIZERS

When individuals have come to their own firm personal decision to stop taking psychoactive drugs, before reducing their dose 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, to bring the withdrawal process to a positive end. 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) are a serious risk. Sleeplessness, mental symptoms, 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. David Richman, M.D., of California writes for example (p. 50):

> "The best way to minimize drug-withdrawal is to reduce drug intake gradually. This is especially important, if the drug has been taken for more than one or two months."[5]

There is a significant risk of developing tolerance and becoming dependent on (minor) tranquilizers even after a short period of treatment with a low dose. Severance from tranquilizers 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 tranquilizers) 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, diarrhea 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). Pharmacists believe that the recent atypical neuroleptics modify subtypes of specific dopamine-receptors and contribute to the risk of new, increasing or chronically powerful psychoses of organic origin. Surveys about medical literature on the withdrawal problems of neuroleptics can be found in the books *Wie Chemie und Strom auf Geist und Psyche wirken (The effects of chemistry and electricity on the human mind and psyche*, pp. 99-104)[6] and *Wie Psychopharmaka den Körper verändern (How psychotropic drugs change the body*, pp. 405-432)[7].

R. Ekblom of Ulleråk Hospital in Uppsala, Sweden, and his colleagues are the authors of a report on supersensitivity psychoses discernible at once 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. Twenty-two months later he developed a dangerous alteration in his blood; the neuroleptic had to be stopped immediately. The psychiatrists recount (p. 199):

> "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."[8]

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

Rudolf Degkwitz, a former President of the German Association for Psychiatry and Neurology, has repeatedly reported on withdrawal symptoms – not publicly, but in specialised magazines (p. 175):

> "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."[9]

George Brooks, psychiatrist at the Waterbury Center, Vermont, says (p. 932):

> "The severity of the withdrawal symptoms may mislead the clinician into thinking that he is observing a relapse of the patient's mental condition."[10]

2. HOW TO COME DOWN FROM PSYCHOACTIVE DRUGS

Desire, will-power and – if necessary – patience are of extreme importance in coming down from psychoactive drugs. The rule of thumb is: do not overdo, be aware that quick changes in the body's metabolism can cause severe withdrawal symptoms. Also, be aware that persons coming down from psychiatric drugs are weakened, particularly when they have just gone through withdrawal. Even if they are symptom-free, their nervous system is not yet stabilized. 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 occur, that they must be reduced gradually and, if necessary, under medical supervision. Particularly since the possibilities are rare of coming down from psychiatric drugs in a sheltered ward, there are a lot of assisting aspects of great importance: contact persons, integration into self-help groups, social relations, access to less harmful substances to help calm severe symptoms[11] 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 psychiatric drugs 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. Some simply threw their psychiatric drugs in the trash, although it should be noted that disposing of these drugs at the pharmacist's is safer for the environment. Others sought support from doctors and therapists (psychotherapy, hypnosis, massage, etc.) or homeopathic doctors, natural healers and from other therapies such as breathing techniques, vitamin cures, colour therapy, acupuncture, etc.[12] (This list is far from complete.) Runaway-houses whose staff reflects the risks of psychiatric drugs can provide a good shelter to withdraw from neuroleptics too, like Kerstin Kempker, member of the staff of the Berlin run-away-house reports in her book *Flucht in die Wirklichkeit – Das Berliner Weglaufhaus (Escape into reality – The Berlin Runaway-house)*[13].

(Ex-)users and survivors of psychiatry who particularly thought of the possibility of relapsing into psychiatry found their own solutions such as autogenous 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.

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 the "psychiatrization" 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.

3. ALTERNATIVES AND MEASURES TO ENCOURAGE WITHDRAWAL

Karl Bach Jensen, the former chair of the European Network of (ex-)Users and Survivors of Psychiatry, developed the most responsible political demands to enhance the situation of people who made the decision to withdraw from neuroleptics and to cope without neuroleptics in psychosocial crises.

> "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"[14]

he wrote (p. 343). His point is not that you shouldn't care at all, 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 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 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 sub-cultural 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. 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 – telling which 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 decentralized services to meet the needs of people experiencing mental health problems would minimize 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: 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 you should

- oppose and fight international recommendations and national laws legitimizing forced psychiatric treatment, especially legally-enforced conditions of long-term treatment in the outpatient sector,
- collect and propagate knowledge about withdrawal problems and how to solve them,
- develop special services and institutions 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.

References

1. P. Lehmann, 1999, Forum – the Declaration of Madrid and current psychiatric practice: users' and advocates' views, *Curr Opin Psychiat* **12**(1):6–7.
2. V. Lehtinen, E. Riikonen, E. Lahtinen, 1997, *Promotion of mental health on the European agenda,* Stakes, Helsinki.
3. P. L. Gilbert, M. J. Harris, L. A. McAdams, D. V. Jeste, 1995, Neuroleptic withdrawal in schizophrenic patients: a review of the literature, *Arch Gen Psychiat* **52**:173–188.
4. B. Woggon, 1979, Neuroleptika-Absetzversuche bei chronisch schizophrenen Patienten: 1. Literaturzusammenfassung, *Internat Pharmacopsych* **14**:34–56.
5. *Dr. Caligari's psychiatric drugs*, 1984, Network Against Psychiatric Assault, Berkeley.
6. P. Lehmann, 1996, *Schöne neue Psychiatrie*, Vol. 1: *Wie Chemie und Strom auf Geist und Psyche wirken*, Antipsychiatrieverlag, Berlin.
7. P. Lehmann, 1996, *Schöne neue Psychiatrie*, Vol. 2: *Wie Psychopharmaka den Körper verändern*, Antipsychiatrieverlag, Berlin.
8. B. Ekblom, K. Eriksson, L. H. Lindstroem, 1984, Supersensitivity psychosis in schizophrenic patients after sudden clozapine withdrawal, *Psychopharmacol* **83:**293–294.
9. R. Degkwitz, O. Luxenburger, 1965, Das terminale extrapyramidale Insuffizienz- bzw. Defektsyndrom infolge chronischer Anwendung von Neurolepticis, *Nervenarzt* **36**:173–175.
10. G. W. Brooks, 1959, Withdrawal from neuroleptic drugs, *Am J Psychiat* **115**931–932.

11. A. Ochsenknecht, 1993, Die seelische Balance – Pflanzenheilkundliche Unterstützung bei psychischen Problemen und beim Entzug von Psychopharmaka, in: *Statt Psychiatrie* (K. Kempker, P. Lehmann, eds.), pp. 82 94, Antipsychiatrieverlag, Berlin.
12. P. Lehmann (ed.), 1998, *Psychopharmaka absetzen – Erfolgreiches Absetzen von Neuroleptika, Antidepressiva, Lithium, Carbamazepin und Tranquilizern*, Antipsychiatrieverlag, Berlin.
13. K. Kempker, 1998, Erfolg in Zahlen?, in: *Flucht in die Wirklichkeit – Das Berliner Weglaufhaus* (K. Kempker, ed.), pp. 270–279, Antipsychiatrieverlag, Berlin.
14. K. Bach Jensen, 1998, Entgiftung – im Großen wie im Kleinen. Für eine Kultur des Respekts, in: *Psychopharmaka absetzen – Erfolgreiches Absetzen von Neuroleptika, Antidepressiva, Lithium, Carbamazepin und Tranquilizern* (P. Lehmann, ed.), pp. 337–344, Antipsychiatrieverlag, Berlin.