

## Antipsychotics Information Brochure

### Preface

For the first time in October 2015, the NetzG RLP – Netzwerk Selbsthilfe seelische Gesundheit in Rheinland-Pfalz (*Network Self-help on Mental Health in Rhineland Palatinate*) submitted an application for funding to publish an “Information brochure on neuroleptics and antidepressants”. The reason given in the application was as follows: “The information pursuant to Article 1.1, and Article 2.2 sentence 1 of the German Basic Law recognises the respect and dignity of all human beings and guarantees the right to physical autonomy. Mentally ill people can only give their proper consent (§ 630e German Civil Code) after they have been fully informed. Information brochures are now a matter of course within physical somatic medicine. Now, for the first time in the area of psychiatric medicine, the pharmaceutical industry has drafted information brochures.”

Dr. Anke Brockhaus-Dumke, medical director of the Rheinhessen Specialist Clinic, informed us of this development. We have now drawn up these information brochures in cooperation with the medical directors or chief physicians and the nursing management of three former regional hospitals, Klingenstein, Alzey and Andernach, and the activists Dr. Volkmar Aderhold and Dr. phil. h.c. Peter Lehmann over a period of 18 months. In an atmosphere of close cooperation, we met regularly at weekends in the academy of Rhein-Mosel-Clinic in Andernach to discuss the principle, the content, the language and the design of the brochure.

We tested the first ideas on professionals and psychiatric patients, discussed their reactions, adapted

our conceptions and results, and present here our preliminary results in clear and in plain language. It is the first known attempt, anywhere in the world, with those treating and those being treated working together, to collate information on antipsychotic drugs with respect to the mode of action, adverse effects, coming off, alternatives and literature on these topics and to publish it in print and on the Web.

We are well aware that this is a first attempt and so are open to advice and information of any kind. We are willing to discuss and to take criticism into consideration in any future versions of the brochure. This is an attempt to bring those who treat and those who receive treatment to the same table, so they can develop their own approach and come to mutually agreed compromises. Decide for yourself how well we have succeeded in our aims. You can see from our information brochure on antidepressants that this work will be continued.

The Self-help Network on Mental Health in Rhineland Palatinate wishes to express their thanks to the ten members of the working group for their commitment and for the result, as well as the MSAGD (*Rhineland Palatinate Ministry for Social Affairs, Labour, Health, and Demographics*) and the TK (*Techniker Krankenkasse; Health Insurance Company for Technicians*) for their financial support. The working group wishes all readers of the information brochure “Antipsychotics”, as well as all those who are interested, a very informative read.

## Antipsychotics Information Brochure

### How Antipsychotics Work

An acute psychosis is supposedly associated with increased dopamine activity, a neurotransmitter (messenger substance) in the brain. Dopamine can have both positive and negative effects on how we feel, whether we feel content and active, and to which external and internal stimuli we react to and how we judge these.

Altered dopamine activity in certain areas of the brain is linked nowadays to episodes of delusions and hallucinations (e.g., hearing voices). Antipsychotics (also called neuroleptics) block the effect of this

neurotransmitter in the nervous system. Also the adverse effects of antipsychotics result mostly from their blocking effect on these and other docking points on different neurotransmitters. Antipsychotics are meant to alleviate or eliminate your symptoms (anxieties, agitation, hallucinations, delusions and other symptoms). In the case of acute symptoms, alongside treatment with antipsychotics, psychosocial therapies also play a key role. Psychosocial therapies include, for example, having a companion, quiet, protection and one-on-one sessions with a psychotherapist, or with someone who is close to you



if you wish. If you are in an acute crisis and choose not to use antipsychotics, a quiet and safe environment is particularly important. You need to get enough sleep, if necessary with the help of sleeping tablets. Reducing tension, for example through sport, movement and other measures, is very helpful. If this does not bring any relief we would advise you to start treatment with antipsychotics. Without treatment with antipsychotics the symptoms might remain or might take longer to abate. In the long term, depending on how things develop, antipsychotics can be used to prevent a relapse. Psychosocial measures such as help from people who have already gone through a psychosis (recovery companion), advice, psychotherapy, or rehabilitation measures may also help to prevent relapse (see “Alternatives to Antipsychotics”).

Antipsychotics are not addictive (in contrast to alcohol or drugs). But they do lead to physical habituation effects. Stopping abruptly can lead to your feeling unwell, agitation, disturbed sleep, anxieties, etc. Therefore, our advice is to reduce or stop antipsychotics carefully step-by-step and to discuss the withdrawal with an experienced companion. If you decide to take this path we would be happy to support you to the best of our ability.

### **Antipsychotics: Possible Adverse Effects**

The frequency and severity of the individual adverse effects vary according to the substance, dose and individual sensitivity.

#### **1. Motor disturbances**

- cramping of the tongue and the muscles of the throat, or visual cramps (early dyskinesia; risk 2-25%)
- limitations on movement, rigid gaze, trembling (drug-induced Parkinson syndrome; 15-30%)
- tortuous restlessness of the legs (akathisia; 20-25%)
- permanent involuntary movement, especially of the tongue, mouth or facial muscles (tardive dyskinesia; 15-20%)

#### **2. Tiredness, loss of concentration, lethargy, resulting in limited driving ability**

#### **3. Disturbances in hormone regulation (increased prolactin level)**

- enlarged breasts, milk flow, lumps in the

breast, also in men

- decreased libido, potency problems
- menstrual disorder and reduced fertility

#### **4. Cardiovascular problems**

- changes in heart rate (slowing down, speeding up) irregular heart beat
- circulatory disorders with low blood pressure
- myocarditis
- thrombosis, pulmonary embolism
- increased number of fatalities among older patients with dementia

#### **5. Metabolic and nutritional disorders**

- increase in appetite and weight
- increase in blood sugar, cholesterol, blood fats
- development or worsening of diabetes
- increased risk of heart attack or stroke

#### **6. Disturbances of the digestive system**

- dry mouth or increased salivation
- nausea, vomiting, obstipation, diarrhoea
- raised liver function values, inflammation of the liver

#### **7. Psychiatric disturbances**

- agitation, sleeplessness, feelings of anxiety
- depression, tendency to suicide
- apathy, slower thought processes

#### **8. Rare life-threatening disorders**

- Malignant neuroleptic syndrome: this condition is associated with sweating, fever, difficulty swallowing, trembling, stiff muscles and disturbances of consciousness including coma (0.02-0.5%)
- **Death by sudden cardiac arrest**

#### **9. Further undesired effects**

- dizziness, headaches
- convulsions
- blurred vision, lethargy
- fluid retention



- increased sensitivity to sunlight, allergies
- difficulty passing water, incontinence
- decreased white blood cells, or blood platelets.

The listed adverse effects occur with the different drugs at different frequencies and cannot be predicted. The desired and unwanted effects only become evident in the course of the treatment. Therefore, it is very clear that the substance and dose must be tailored to your needs and experiences.

**If you are pregnant or nursing you need clear focussed advice and you need to weigh the risks and benefits as early as possible. To avoid injury or to assess adverse effects, right from the beginning and throughout drug treatment a number of tests need to be conducted in an outpatient setting (e.g. blood tests, ECG, pregnancy test).** More information is available on the following:

- reducing and coming off antipsychotics
- alternatives to antipsychotics
- other aspects.

### **Reducing and Coming off Antipsychotics**

Numerous studies have shown that antipsychotics are discontinued by up to 75% of patients within the first half year of the prescription. There are multiple reasons for this, most commonly adverse or insufficient effects as well as patients' desire to manage the psychosis on their own without taking drugs. The risk of a renewed psychotic episode following an abrupt withdrawal is markedly increased. The biggest risk of a relapse is always during the first one to two years after withdrawal. However, an individual risk assessment is not possible. By changing your individual risk factors, you can reduce your own risk of relapse. There is no one-fits-all prescription for reducing the risks when stopping the drugs. Nonetheless, a number of people have found the following quite helpful:

- Find out about any phenomena associated with withdrawal.
- Plan the withdrawal process, preferably under therapeutic supervision.
- Inform sympathetic close friends or relatives and consider developing a crisis plan.
- Choose a suitable time (with a minimum of external stress factors).

- Get advice, for example from people who have experience coming off psychiatric drugs or from recovery experts. In other words: join a suitable self-help group.
- Make sure you are in the company of those who understand withdrawal from psychiatric drugs.
- Take nutritional substances and substances to stimulate metabolism.
- Get legal advice; draw up an advance directive, draft a crisis plan, agree on a treatment plan.
- Make sure you are in a quiet environment; keep your distance during the withdrawal period from relatives who are either stressful or who are themselves easily stressed.
- Be physically active; go for walks, go hiking, cycling, jogging, dancing, swimming, do gymnastics.
- Eat properly, eat well (eat fibre, whole foods, salad, fresh vegetables, fruit, diet if appropriate, drink lots of fluids).
- Eat regularly, but not too much; consider cutting down on drinks such as coffee or black tea and alcohol.
- Be good to yourself, listen to relaxing music, read literature that does you good, stay in contact with friends.
- Live mindfully; write letters, keep a diary, keep a log of the withdrawal process.
- Above all, ensure you get enough regular sleep (before midnight). Other effects can occur after dose reduction or complete withdrawal. There is currently no reliable data available on the frequency of these effects.

1. Restlessness: this can be expected, especially following dose-reduction and withdrawal from strong sedative antipsychotics, as the sedating effect reduces. This can manifest itself positively in that you feel less tired and your cognitive performance improves, e.g. concentration and attention span improve. In the worst case, symptoms of severe restlessness including anxieties and severe sleep disturbances.

2. Movement disorders can occur: even after stopping antipsychotics, rare movement disorders can occur, similar to the beginning of antipsychotic therapy. If



tardive dyskinesia has occurred while you were on antipsychotics this may persist and even temporarily worsen after withdrawal.

### **How to Withdraw?**

Based on current data, the step-by-step withdrawal of antipsychotics is the best approach to avoid the risk of a recurrence of psychosis. The time it takes to withdraw from antipsychotics depends on how long you have been on them. After taking antipsychotics for several years they should be withdrawn over a period of several months. Proposal: reduce the dose every six weeks by 10%. If the withdrawal symptoms are too strong, then go back onto the previous dose; several attempts may be necessary, even considering a dosage every other day (one day on, one day off). Drops are more suitable to make very fine adjustments. Even the reduction of the dose is a success. Gradual withdrawal can, and in fact should, be carried out in an outpatient setting. Hospitalization may be appropriate if the withdrawal effects are too strong or you suffer a further psychotic episode. Beyond that, no generally valid recommendations can be made at this point. You should discuss the individual early warning signs of a relapse, e.g. restlessness, sleep disturbances, anxieties, mistrust or other symptoms with your doctor or therapist and especially with someone close to you. This can help in case a relapse threatens and the reduction of the antipsychotics can be stopped or slowed down.

### **Alternatives to Antipsychotics**

If you would prefer the safety and support of a clinic but don't want to take antipsychotics, the following options are available:

- empathetic patient chaperoning by personnel, protection from too many stimuli
- conversations with other patients, recovery companions
- psychotherapy (cognitive behavioural therapy, systemic procedures, deep psychological procedures)
- psychosocial help and social counselling (e.g. for problems with work, living, finances)
- information sessions, e.g. psychosis seminars, self-help groups
- naturopathic or homeopathic remedies (e.g. valerian), aroma therapy, acupuncture
- sport, physiotherapy and relaxation techniques (jogging, gymnastics, swimming, table tennis, yoga, meditation, autogenic training, etc.)
- creative therapies and ergotherapy (dance, music, or art)
- special nutritional measures (e.g. nutritional supplements)
- communication with benevolent confidants, if necessary using social media (e.g. Skype or email).

These are also helpful if you are taking antipsychotics. Choose the hospital and treatment that are best suited to you and your needs. Psychiatric drugs are generally only one of several treatment methods. In accordance with the law and treatment guidelines, it is the patients who decide which option to choose.

*Translation by Mary Elizabeth Murphy*