

## Topic

### I have been HIV-Positive for Five Years

**Alexandra Volina** Once a waif, all in rags, dirty, with a syringe in his hand ran up to her in the street, caught her sleeve and cried out: “I have AIDS, give me a hundred roubles, if not, I will infect you!” Alexandra answered: “You are HIV-positive? Great! Me too”.

There is such a notion – to accept your diagnosis. Since, on the one hand, at first, one knows that s/he is HIV-positive, but on the other hand, pretends that it is not true. There are two possible ways here. Having found out that they are infected some people decide – to hell with it, let’s have fun in the end! But it becomes the beginning of a new life for some others. And they give up drugs, alcohol, enter the university, and start working... I implemented my fear into my work. We are working very hard now, from morning till night. *We* means a group of activists under Front AIDS. We help those HIV-positive people who are dying. We cooperate with the Botkin hospital – it is considered to be very rare that HIV-positive people look after such patients... Then, I am the director of the “Svecha” charity foundation that provides assistance in social questions: we help them to get jobs, find lodging, we still have some guys living in our office, their parents have turned them out of the house... We are involved into informing as well. Many people do not know at all what HIV and AIDS are, and how to live if you are HIV-positive. And the most important aspect of our work is mutual help group and psychological support.

This work is very challenging. For instance, one girl calls me at night when her mother is asleep. She is sixteen, it was her first boyfriend and now she is HIV-positive – what should she tell her mother? It is extremely difficult.

And certainly, we cannot do without fighting for our rights. And the biggest problem is this ARV, tritherapy. One takes three pills a day and if one is already ill, AIDS gets back into the state of being HIV-positive. As a matter of fact, one can live as long as possible with ARV. But this medicine is not given to everybody; it costs 12 thousand dollars per year, and in St. Petersburg we constantly observe all kinds of irregularities, problems and delays – that’s why patients are picked out on the basis of being socially promising. If you are socially promising, you will get ARV, you will go on living. If not, you will die. And many die because doctors came to this conclusion. I do not need pills so far. Though, I will no doubt need them soon. Soon... It is the sixth year.

Another thing we are fighting for is PR. We are all intimidated with AIDS, with the slogans “AIDS means death”. This homeless boy who demanded money rushed away with wild cries! And many people are afraid even to be near us. If you want to have your teeth treated or go to the gynecologist and you say that you are HIV-positive, no one will treat you. That’s why I always say that I have hepatitis. We want to arrange a special training – for doctors... And it is many times easier to contract hepatitis. HIV has already been officially moved up into the category of chronic diseases out of the category of terminal diseases. It is almost the same thing as diabetes. But then one constantly needs insulin and we need ARV.

Now doctors tell you the diagnosis carefully, with psychological preparation. And when I found out about it five years ago, all the staff of the polyclinic gathered to have a look at me as if I were some mysterious beast. I was about 20 years old. The doctors said: “That is it, girl, you are HIV-positive, you can go wherever you want.” I found the AIDS center only several months later and started adjusting myself to the new circumstances. Unfortunately, I did not manage to finish my education. I finished only the first year in the department of psychology – I was ill in the second year...

I work a lot; sometimes I don’t even have enough time to cook. My husband and I want to have children, but there’s been so much work so far that it is not the time yet. My husband’s name is Sasha, too. Sasha and Sasha. We got acquainted while attending a mutual help group. Yes, he is no doubt HIV-positive as well. So what? If one does not take ARV, one can be 90% sure that the child will be absolutely healthy. And if one takes the pills at a certain month of pregnancy, one can be 99.9% sure. The “Namedni” program even made a film about our wedding...

I used to appear on television and in some actions in a mask with openings. And then I thought: they view us as drug users, commercial sex workers, men having sex with men or AIDS-terrorists! And the mask enhances this impression. We fight for living an ordinary life, and at the same time we hide ourselves! I told my mother: “I am going to open my face. All your acquaintances will learn that I am HIV-positive. Are you not afraid?” But my mother is wonderful. She said: “I am not ashamed of you, I am proud of you”.

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