

A LITTLE SUNSHINE IN THE COLD WATER

Name: IRINA,
Country: KAZAKHSTAN

So, let's get acquainted. My name is Irina, I am 38 years old and I have been living with my boyfriend in a civil partnership for over nineteen years. We haven't had any children during our life together because most of it has been spent on heavy drugs and on "business trips" to detention facilities. This was also the reason why we ended up in the opioid substitution therapy (OST) programme, as we wanted to be done with our dependence.



I now realise that the programme is primarily about reducing the frequency of injecting various opiates and not about getting rid of them altogether. When I joined the programme, I initially hoped to raise my dosage in six months, then lower it and then get out of the programme safely, but it took me a while. Despite all the difficulties, my partner and I live together in a small cosy flat not far from the OST site. I would also like to say that I am from Ust-Kamenogorsk, which is in the east of Kazakhstan.

In my spare time, I draw, read books and go jogging in the evenings. I love nature, walking outdoors, ice skating and hiking in the mountains. I could tell you many more things that I love, but life is very limited. For instance, because of the substitution therapy programme, we have no opportunity to go on a trip to the countryside with our parents or with

a group of friends for a couple of days because we are not given any take-home medication. It is a shame to say, but I haven't been to the seaside for fifteen years. This situation is one of the problem spots in the programme.

Should such a trip occur, if all initially goes well, by the evening of the first day, my well-being will begin to deteriorate due to the impending withdrawal syndrome, and it will then only get worse and worse. It will not just be a bad holiday; it will be totally ruined, not only for me but also for those around me. I will be nervous, rude; my loved ones will feel sorry for me and give unnecessary advice, especially if it's my mother or friends who do not understand the intricacies of my well-being. Therefore, for the time being, my only recreation is a beach on

the bank of the Irtysh River, where the water is very cold, or the muddy Ulba, covered with litter along the entire bank.

The journey from point A to point B

My daily journey from home to the site takes from fifteen to twenty minutes on foot through courtyards, past shops, kindergartens, schools and the library. The pharmacy is the most interesting location on my route. Coincidentally, it is one of those pharmacies that dispense illicit drugs without a prescription (tramadol, Somnol, dimedrol, tropicamide). You'll almost always find interesting faces here, including police officers looking for the next victim. Nearly every day, there are some curious incidents here. By the way, some of our patients are quite frequent visitors to this place. I don't judge them because I was one of them myself for a while.

Next, I walk over the pedestrian crossing, and the red light has been on for almost two minutes. I wait for the green light and look at the zebra: a black stripe, a white stripe – just like in our lives. Today things are bad, but tomorrow, they will change for the better. It rains in the morning, and it is sunny in the evening. Everything in the world is ever-changing. But in our life, nothing changes. Laws are changing, officials are changing, medicine is advancing, new technologies are emerging, e-learning is on the rise, etc. During the pandemic, many areas of life, in general, have become distance-based: food delivery, online shopping, online platforms for various events.

The whole world has started to live by new rules. But we cannot change anything in our little

world of substitution treatment programme because the people who set these rules do not want to hear us and do not want to know about our problems.

In the very first lockdown, most developed countries adopted measures in their opioid substitution therapy programmes allowing at least five days of take-home doses. We were not among those countries. In Kazakhstan, the substitution therapy programme has been a pilot project for eleven years. Just as we would go every single day to the narcological dispensary for a daily dose, we still do. Be it a pandemic, extreme heat, frost or no transportation service – no big deal, we manage to find a way in any hopeless situation.

After all, we have been through fire and water, especially during the time when we were in an irregular situation. Why feel sorry for us? Even after surgery, we would still come the next day on crutches and climb up to the fourth floor for a glass of this “life-giving water”. I remember a case like this: I've taken my “dose”, and going down the stairs, I find one of our patients, who has just had a kidney removed, climbing up to the fourth floor. He walks up, quite briskly, with a tube sticking out of his side, from which some liquid is dripping into a glass jar he carries in his hand. Yeah, that's how we live.

A building with bars on the windows

The building of our narcology department is in the middle of a residential area, almost in the city centre. You can get there by bus from anywhere in the city. However, the problem is that buses are running late, and they are usually overcrowded. And

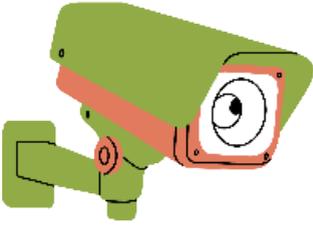


now it's still hot, up to forty degrees, it's summer, and again the pandemic isn't over and wearing masks in public places is obligatory. The premises of the narcology clinic are a dull five-storey building with barred windows from the ground floor to the third floor. The building has two entrances. The first entrance is the narcology department, and the second one is the psycho-neurological department for children.

And now, let's have a little tour to see what's inside the first entrance. The ground floor houses the regional AIDS centre, where five other patients from our site and I work as outreach workers. By the way, it is very convenient, but unfortunately, not all folks are so lucky with their jobs. So, I combine, as they say, business with pleasure. Sometimes I have to consult people looking for the AIDS centre, accompany them and provide them with psychosocial support. Further up, on the first floor, there is a children's psycho-neurological ward. On the second floor, there is an in-patient unit for people

with alcohol dependence. On the third floor, you find the administration and registration office of the regional narcology clinic. Finally, on the fourth floor, there is a polyclinic and a methadone dispensary, as well as an in-patient unit for people with substance dependence.





Coming to the dispensary I go up to the fifth floor every day, to the right along the corridor, the second door on the left is the methadone dispensing office. The room has a two-by-two-meter barred window. The other part of the room where the nurse is located is fenced off with bars too. Through this bars that they give us methadone. There is a CCTV camera in the patient room, and the monitor is in the part where the nurse is sitting.

In the nurse's room there is a safe, a refrigerator with water, two tables. On one of the tables are our cards with names and appointments.

Another counter is the one where they pour methadone for us. There is a bottle of methadone syrup and a porcelain bowl into which the syrup is poured. From this bowl, they take out our dosage with a 10-cc syringe and pour it into plastic cups, top it up with plain water from the bottle and then give it to us. We take our dosage and

have an extra cup of water. On the windowsill, there is a water bottle and some plastic straws for cocktails. There's this alternative: you can drink it through a straw or chug it down if you like. There are also some announcements and a dispensing schedule in our part of the unit. In terms of the schedule, methadone is dispensed between Monday and Friday from 7.30 am to 9.30 am. There is a break from 8 am to 8.30 am so that the nurse can fill out patient cards and use the bathroom.

At weekends and on public holidays, methadone is dispensed from 8 am to 10 am. Sometimes, if the nurse is late or opens at 7.30 am sharp, there is patient outrage about this. The folks shout to the nurse: "You're late, we're late for work too, it's hard enough for us to get a job anywhere." But the site usually opens at 7.20 am. This working schedule is another problem, although not the

most important one. Once, in the early months of the site's work, it was possible to come here at any convenient time from morning until evening. Then, for a while, the site worked from 7.30 am to 8.30 am and additionally from 2 pm to 3.30 pm. Now, it only works in the morning. I think this has to do with funding. The nurses in the dispensing room were paid full-time back then, and if this continued now, it would be easier for us... And the best thing, of course, would be if they started to provide us with take-home medication for a week.

I go there at different times when it's convenient for me, within the given timeframe, of course. Sometimes it's just going there and back home, but sometimes I go to the AIDS Centre a couple of times a week to get "handouts" for my work. So today, I picked up some handout materials, and as I walked past the pharmacy, I met two guys,



very young, about 18 years old. I just happened to overhear them talking: "Let's get the spikes and go to our place." I said to them: "Guys, take them from me." They were surprised and even a little scared, wanting to give me money. But I explained to them that everything was free. I also told them that I could anonymously perform saliva tests for HIV and gave them a short lecture on safe use. After all, it's my job, which I enjoy.

My whole life is about drug harm reduction. I work in this field and am a patient of substitution therapy – an important component of harm reduction. I care about my life and the lives of people who use drugs, so whenever possible, I try to take part in all events and activities that can change the drug policy of our country and somehow make the lives of people who use drugs better and safer.

This is how my normal days go: home – OST site – AIDS Centre – home – outreach visits – home. At weekends, I go to my parents' country house. It's pretty repetitive, isn't it? But I always find something to make it more diverse: walks with someone dear to me along the riverbank on a chilly evening, a delicious lunch or dinner cooked with love, going shopping, reading a book or watching a favourite film. That's how daily life goes in my little world.

You have to work

Staying on the programme involves working with a good psychologist who can advise on how to properly set priorities when leaving the programme and help to cope with changes in the psycho-emotional state when the dose gets lowered. A good psychologist joined the team of site workers five or six years after it opened. Before that, we had another psychologist, but he was there, so to say, just formally. Simply present, I would say. In fact, everything changed six years ago when a new doctor arrived – one of the leading mentors of opioid substitution maintenance therapy programmes in our country. In my opinion, he was the one who got the site up and running.

As the programme coordinator, he introduced mandatory monthly meetings with each patient to adjust their dosage, where he would ask questions about how we were feeling, how we were doing and how we were flowing into the stream called social life. "You have to work", says the doctor. Against the backdrop of the general indifference in which we had been living for about five years since the start of the OST, we were very much annoyed by these innovations. But we had to put up with them.

Many people understood and accepted his tactics and strategy, including me. I think it is correct and agree with almost all the recommendations. Others, though they don't like it, have no other choice. They go around muttering something and sometimes trying to voice their discontent: "Why should I go to a psychologist every month? What can he tell me? I am my own psychologist." Our doctors get rather tough on such patients: read the contract, clauses 2 and 3, where it is written that the patient is obliged to see a psychologist on a monthly basis. By the way, there is a copy of the contract hanging in our room in case someone has forgotten the terms of the contract. The contract is written in such a way that in the patient's rights section, every sentence starts with the words "the patient MUST". Any slip-up on our part and the contract is unilaterally withdrawn.

Speaking of motivation, when someone comes here for the extra high, they tend to drop out if they don't understand the essence of the programme. The measures for those who violate the agreement are harsh – expulsion from the programme. Not immediately, of course, but in the form of reduced dosage: 5 mg every fortnight, 5 mg every week, 5 mg every five days or 5 mg every three days. It depends, of course, on the gravity of the offence. On our site, for example, when additional use of pharmacy drugs (tropicamide, dimedrol, Somnol) is detected, they first hint several times, "You have lost weight, your complexion is grey." Then, they say that "you have been

seen frequenting the pharmacy” or “you have been seen in an inadequate state” (sometimes you even get the feeling that our doctors do nothing but keep tabs on us).

Next comes a warning to stop taking drugs, a final warning, calling your parents or spouse, depending on who you live with. If none of the above helps, they convene a committee of doctors and a psychologist or involve a patient council, where the offender has to promise not to use any other substances. If this does not work, the patient is prescribed a reduced goodbye dosage. Then, after decreasing the dosage to the minimum, the patient can be hospitalised for detoxification.

Much to be desired

According to the folks’ feedback, detoxification also leaves much to be desired. Patients go on a fast-track programme of dose reduction for trying to get their methadone out of the unit. The doctor would say to such folks, “Thank me for not calling the DEA (Drug Enforcement Administration) but just saying goodbye to you.” And nobody cares about what happens to these people afterwards. My experience shows that most of these people do very poorly in the future; some even die.

Why does this happen? Why do some people, when they come to the programme, get a job, socialise and live a normal life, while others continue to use and need to find more drugs? Why don’t doctors ask themselves this question but ask us, and instead of looking for answers, choose punitive measures: punish, expel from the programme? Maybe we just need to expand the range of drugs, as we still don’t have buprenorphine in our country.

There are forty of us on the site now, and everyone has a different dependence index. Some need a shot of dimedrol, some need a beer and some need something else entirely different. And the approach to all of us is the same – coercive and punitive, just like all drug policies in our country.

There have been cases when some of the folks would take too long to get their annual X-ray, and an ultimatum would immediately follow, “If you don’t bring the test results tomorrow, you won’t get the methadone.” Is this the right approach to health care? Yes, we are not very well organised, but this is only because we have lived our whole lives in fear of people in white coats and uniforms, clad in power. We are used to going to hospital only as a last resort. Even now, I think, since the coronavirus pandemic began, more than a half of us have had the flu or coronavirus without disclosing it due to the fear of confinement and the possibility of having to stay without the life-saving medication.

Many of us, participants of the substitution therapy programme, hospitalised with another condition, had to break the hospital regime and escape from it to go to the site and get the medication. In my opinion, the most important thing is continuity of access to substitution treatment during hospitalisation. I would also like to say that in our country, there is no access to substitution therapy in prisons either. If our patients are incarcerated, they have to go through the excruciating pain of withdrawal from the drug.

Ideally, we would like the site to be organised in a way that meets all the individual needs of patients, e.g., social assistance with all sorts of insurance and benefits, as well as training and job placement. It is important that we have our own space where patients can spend time after taking the medication (to get warm in winter and hide from the heat in summer). And, of course, we need two or three more sites in other parts of the city, as well as access to the medication during hospitalisation, home care and take-home doses. And I believe that with the joint community effort, we will achieve all this!

Irina Selina, Kazakhstan

[More stories on the EHRA website](#)