

MY LIFE-LONG DAY

Name:

OLENA,
UKRAINE

Country:

Expired Passport

The bus stopped at the checkpoint. My heart froze, my stomach shrank... I got up at dawn today. The Donetsk–Sloviansk minibus left at 5 am. I didn't even have breakfast, as I was to receive methadone not in the Donetsk People's Republic (DPR) but in Ukraine today.¹

I was shaking with fear as I travelled –

all I needed was to get to the clinic just to get there on time.

Opioid substitution therapy (OST) site in Donetsk was on its last gasp – it was running out of medication. From that day on, the doses were cut in half for everyone. My 50 mg became 25 mg, and soon, that would be gone as well.

The methadone destined for the Donetsk region was lying unused in the Lika Ukraina warehouse in Kyiv, bound to stay there.

I was on my way to Sloviansk as part of the programme called “Displaced Persons” by the Alliance for Public Health. This small resort town, famous for its salty lakes and medicinal mud, where the turmoil in the Donbas region began, was where my relatives lived. That is why I didn't have the feeling that I was heading nowhere. Although I was still very scared, I was afraid that I would not get through because my passport had expired.

A Ukrainian soldier, a young cheekbone freckled fellow, looked inside the bus: “Citizens, where are you going? Home?” “Yes, home”, the

passengers answered in discordant unison. The soldier moved down the aisle, quickly checking passports. Following a travelling companion's advice, I put 50 UAH into my passport. As he left, he wished me a happy journey, and the bus started – I'm already in Ukraine! I took a breath. I got through! I will be on the programme!



Back to the future

The whole of 2014 and the first five months of 2015 were terrible with the uncertainty and the constant expectation that I would come in the morning to get the medication and the programme wouldn't work.

I didn't come to OST myself.

It was my son who dragged me there – after two years of using

“krokodil” (home-made desomorphine), I had fallen very ill. My legs, destroyed first by intravenous and then intramuscular injections of desomorphine, did not want to hold me. While my son arranged a place in the programme for me and the necessary papers were being prepared, I was lying at home, suffering from several simultaneously ripening abscesses and panicking that I simply would not live to see the programme. Although there was plenty of “krokodil”, there was nowhere left to inject it. And on the second day of withdrawal, I began to develop acute renal failure; I was so swollen that I couldn't open my eyes.

I remember the first time I received methadone. It was a real treat. That's it; I don't have to inject that unthinkable painful and poisonous "krokodil" anymore! I am going to live!

However, I had to stay in the ward for a very long time because I could barely crawl: first on crutches, then using the wall. How would I manage to take two means of transport to get to Budyonovka every morning? After breakfast in the ward, I would slowly crawl down from the third floor with a bottle of water in my hand, waddle to another building where there was an OST unit, take my medication, then crawl back, wait for my son to bring me a food parcel, and then sleep, sleep, sleep...



When it got easier, I moved home. And then, as my new OST patient friends said, I "drifted back", or, in other words, came to my senses: I got a haircut and dyed my hair. Soon, the

abscesses healed, and my elephant legs began to return to normal. I felt incredibly free. And when old acquaintances came over to prepare "krokodil", I just didn't open the door. I had new interests and new friends. I was happy. But then the war started, which took that happiness and freedom away from me.

That very woman from Donetsk

And so, I got out of Donetsk and felt free and happy again – I was on my way through Sloviansk to the drug treatment centre. This treatment facility amazed me. After the shabby walls of the OST clinic in Donetsk, the gloomy corridor and the cracked floor, it was clean and freshly painted, with lace curtains. Carrying a bag with all my belongings, I walked through the clinic in search of the doctor.

A big old woman with an angry face and crinkly lips was sitting in the office. Instead of "hello", she asked me, "What? Did you come to gobble up someone else's pills?" Then, she looked at her

watch and informed me that I had arrived too late and would not get the medicine today. I objected, "Well, it's only twenty past nine, and the site runs until half past ten!" Then, the doctor looked at me as if I were a little bug who suddenly burst out with a voice. "I still have to examine you and do your paperwork."

I'm ashamed to say that, but I started to cry and beg her. "All right", said the doctor condescendingly. "Give me your papers."

I said, "It says 25 mg, but look, just yesterday I was on 50 mg, and my recommended dose is 50 mg." After that, I was told that it didn't say

¹ In 2014, Russian military forces occupied part of the Donetsk and Luhansk regions of Ukraine. In the occupied part of the Donetsk region, the so-called Donetsk People's Republic (DPR) was formed. Due to the fact that OST is prohibited by law on the territory of the Russian Federation, the same rules were adopted on the territory of the occupied Crimea, DPR and Luhansk People's Republic (LPR), closing the OST programmes, as well as condemning those patients who receive the treatment on Ukrainian territory for drug smuggling (Free Natasha Zelenina <https://www.facebook.com/FreeNatashaZelenina>).

anything (it was a lie because I had read my papers), that it would be my doctor who could increase my dose, but she was on leave until next Monday (and it was Friday), that I was presuming too far, and that I shouldn't try to be clever, or else I would be sent back home!

The doctor took me to the OST room, where I was given 25 mg of methadone, then made me undress and examined me with a magnifying glass – my groin, my armpits and everything else... When I went outside, my only wish was to cry and go back home. But I pulled myself together and called my aunt Natasha. We agreed that I would call a taxi, pick her up at the psychiatric clinic where she worked and then we would go to her place.

It was when I hung up that I realised that I didn't know how to call a taxi in Sloviansk. I picked up my bag and walked towards the road. There I saw a shop called "Prichal" and a café nearby. There was a guy smoking near the entrance, clearly an OST patient. He asked where I was from and, when he found out that I was that very woman from Donetsk who was supposed to come to the programme, he called out: "Alyona!" A tiny young woman with beautiful and long blonde hair came out of the café. That's how I met Alyona Begunova, a social worker from the organisation "Nasha Dopomoha". She did a lot for me in the first days: she helped me get settled in Sloviansk; my father transferred money to her card; several times, I overslept, and her husband Grisha rushed to pick me up on his moped and bring me to the programme. I knew that I could always turn to this incredibly energetic little girl, and she would always come to help.

Alyona treated me to a coffee and just bombarded me with questions. And when she noticed that I was dumbfounded after talking to Kravchenko, she said that I would have another doctor named Mikhaylova and that it would get much better. It did turn out to be better, but how much better? Kravchenko wanted to re-educate and punish us. Mikhaylova was just indifferent to everything.

50 mg dose

And so, I got out of Donetsk and felt free. Two days on a half dose seemed like hell. The gidazepam and sonnat prescribed to me by my aunt, a psychiatrist, made things a little smoother. On Monday morning, I met my doctor and the head nurse at the clinic. The head nurse also accused me of coming to steal from their patients and told me that I would have been better off staying at home.

Needless to say, my dose was increased to 50 mg by five mg at a time, and my doctor made me take a GGT blood test before each increase to that pathetic five. To take this test, I had to buy a blood draw kit from the pharmacy and turn up at the site by 7.30 am. GGT is just a gamma glutamate transaminase, a liver test. One day, there was a mishap. When my dose was close to 35 mg, my doctor suddenly announced that she would not be increasing it anymore. "Why?" I wondered. "Because your tests show you've had enough methadone." I was taken aback, "What tests?" Mikhaylova replied nonchalantly, "GGT." She forgot that I was also a doctor, and therefore I am well aware that the result of this test can at best show how the barrier function of my liver works. And that was it! At that point, I did something stupid – I laughed and made a joke: "So you, Galina Yurievna, will soon receive a Nobel prize if you have learned how to measure subjective well-being of substitution therapy patients by liver test." She didn't even blush, but I soon regretted it very much.

At first, in Sloviansk, I revelled in freedom and security. And also, legality – I could walk around late at night without the fear of being caught and sent to some basement without trial or even being killed. I could no longer hear the annoying roar of the cannonade. My methadone would be there the next day and the day after that, and no one would take away my substitution therapy. I didn't even pay attention to the blatant boorishness of the medical staff and the stigma prevailing on the site. In Donetsk, I was used to friendly

and tolerant doctors and to being addressed in a polite way, so the contrast between the treatment of patients in Donetsk and Sloviansk was very stark.

It was the summer of 2015; Ukraine had already introduced self-administration. But under chief physician Liapin, take-home prescriptions were like the kingdom of heaven, far away and unattainable. By the way, I only started to receive the medicine for self-administration in 2020, when I was transferred to a family doctor.

Dirt under good people's feet

Day after day went by in the same way, like a copycat. I woke up, got dressed, went to the site. There, I would stand in a queue, the nurse would grind my dose in a mortar, put the powder in a glass of water, I would drink the medication, then walk across the street to a café to have a cup of coffee with my methadone. A lot of people did that.

Then, we would move tables in the café together and sit drinking coffee and chatting until noon. The medical staff did not approve of our visits to the café. But even our chitchat gave Kravchenko information: there were her snitches and provocateurs among us. As soon as we said something inappropriate at the café table, it immediately became known to the medical staff. Yes, it was an empty and meaningless pastime. But what else was there to do for people who could not find a job because of the work schedule of the OST unit? As a matter of fact, apart from the programme, we had no other content in our lives. In the afternoon, I would go home, eat something and go to bed. I would wake up in the evening, read and surf social media. The monotony of life was sometimes diluted by incidents and deaths of patients.

One day, I was sent for a test. I had to take a rapid urine test before the site closed – it was not a legal requirement but a whim of the medical staff. I arrived at the site 15 minutes before it closed. The nurse Irina kept rushing me and making me drink water, but I couldn't

urinate. Moreover, I had peed a lot at home before leaving. Besides, I practically have one kidney, and I usually suffer from oliguria (a small amount of urine).

There were seven minutes left before the end of the working hours, at which point Irina proclaimed: "Do what you want, but if you don't take the test, I won't give you the medicine." At the time, I was completely unaware of the regulations on substitution therapy and had no idea about my rights, so I was very scared. I cried and ran to my doctor, "Galina Yurievna, I can't urinate!" My doctor, calm as a boa constrictor, asked me, "Why are you crying?" I burst into tears, "Because Irina won't give me methadone without a test." "Ah, well, drink some water or something, relax the sphincter." And the damn sphincter didn't want to relax, and a sleepless night of withdrawal was looming in front of me.

I don't get it; did these people in white coats really enjoy humiliating and torturing me? I know now that my rights were flagrantly violated at the time. But back then, I was totally clueless about it, I was a scared displaced person who was told on the OST site that I should be happy that as a miserable separatist, I was even admitted to the programme, that I was a drug addict and nonentity, a subhuman, a scum, dirt under good people's feet, a criminal, deprived of rights, and my disease, along with syphilis and leprosy, was a public hazard (this was Dr Liapin's actual statement at the meeting of the OST site).

A lifesaving call

I couldn't take the test. The site closed. They would not give me any methadone. I went to the quay, miserable and weepy, and I met Alyona there. She was the one who advised me to call the OST and Dependence Hotline. That's what I did: I called and told them what had happened. A few minutes later the operator, a woman, who sounded young, called me back, "Doctor Mikhailova said that she didn't give you the drug not because you didn't pass the test, but because, according to her, you were so heavily intoxicated that she was just afraid of an overdose."

At that moment, my tears instantly dried up, and my resentment was replaced by indignation and then by cold, sober anger. Not only had I been left high and dry, but I had also been slandered. I had grown up in a family of doctors and had never queued at the health centre to get an appointment, nor had I experienced any abuses that medicine is full of,

and has been, and will continue to be. I had lofty and romantic ideas about doctors, so this unapologetic blunt lie by a doctor, a representative of a profession that requires humanism and decency, shocked me tremendously.

And to be honest, it didn't just shock me; it wounded me to the core. At that moment, I decided that I needed to wipe my tears and grind my teeth. And so I did:

I wiped my tears, blew my nose, drank three cups of coffee, then waited until I had to pee, returned to the hospital, took the test, which was negative for the five indicators, took the paper with the result, went up to the resident's room, calmly put it on the table in front of Mikhailova and, looking into her eyes, I asked: "Deeply respected Galina Yurievna, please tell me, by which clinical signs did you determine that I was in such a state of deep drug intoxication that, as you told the hotline operator, you were

afraid to give me the medication to avoid an overdose? Here is the result of the test." Do you think she was embarrassed and started muttering excuses or apologies? No way! Her gaze was clear and serene. "Are you offended that I decided to test you? We have a right to do that!" She didn't even understand the reason for my indignation. Is it even possible to slander a "junkie"? Do these beings have any sense of dignity? Darling, what are you talking about?

An angel kissed me on the forehead

This is just one case out of many that were systemic. I think back to that time, and it was a real swamp, a routine, the same days replicated. The programme in the morning, coffee and gossip, gossip, gossip. Then gossip again. In the evening, there is "weed" if you have money and are lucky. And then, there's the telly and the squabbling, squabbling, squabbling – just out of dullness, boredom and an idle brain.

Then I got lucky: I found a job as a guard at a car park. The pay was ridiculous, but I could read for the entire shift, "devouring" in one year everything written by American and Russian fantasy authors; I re-read Feuchtwanger, both Manns, and many others.

The cabin is warm, the blizzard is blanketing the cars, and I am revelling in Umberto Eco's *The Name of the Rose* for the tenth time. I'm reading it, and I'm enjoying myself terribly because I understand this book completely, down to the last word. It's not just understandable. I am reading this complex text riddled with allusions and innuendoes; I take pleasure in learning the history of literature, the history of language, the history of the Catholic Church, the history of art. At this moment filled with pleasure and joy that I am so educated and clever, a thought comes into my mind, "If you are so awesome,

what the hell are you doing here, doing a job that even a fool can handle?”

This was the beginning of my rise: from an almost vegetal and mindless existence to a full, fruitful, interesting and real life. I had a dream of working for the Alliance for Public Health. At the time, I had no idea what the Alliance did. But I thought I would be able to put my knowledge and my medical degree to good use there. Although it didn't work out the way I thought it would, my dream did come true. I am working for the Alliance for Public Health, but on the editorial board.

And then, an angel kissed me on the forehead, and I woke up an activist. It was probably because I had never been able to get past abuses before, I could not tolerate injustice and I could not see the weak and vulnerable being hurt. And who is more vulnerable in this world than a drug-dependent person?!

How does my day go now? Quite differently. In the morning, I take my self-administered medication, which is the only bit of routine left in my daily schedule.

And then, a day full of all kinds of work begins, filled to the brim with important things to do. I write, I help, I defend and sometimes I study. And when this interesting and colourful day ends, I feel terribly tired and satisfied. And although I sometimes fall asleep sitting at the table during dinner, I am truly happy. Today I am no longer the Lena who came to Sloviansk in 2015; I am a completely different woman – strong, brave and free.

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