

Coping With Cancer: Patients Struggle in Faulty State System

By Natalya Krainova

December 16, 2012



Gritsai sitting on a hospital bed while making an appeal for donations in a YouTube video posted in September.

This article is the first in a series. See below for related articles.

When Maria Gritsai was diagnosed with late-stage cervical cancer, she didn't spend much time grieving. She knew she had to act fast.

With the support of her husband and son, she turned to the Blokhin Cancer Center, one of Russia's best oncology hospitals, where the diagnosis was confirmed. Doctors there also gave her some devastating news: At such an advanced stage, her cancer was incurable.

But she was determined to fight. She began a series of treatments, including home chemotherapy sessions that came with harsh side effects, and bought a costly medicine

a doctor said she needed to stay alive that would have taken four months to get from the public health care system.

The chemotherapy diminished the tumor, but Russian doctors said they could do nothing more after the sessions were completed.

After her chemotherapy treatments, Gritsai was "officially sent off ... for pain treatment and to live out the rest of [her] days," she wrote in a <u>blog entry</u>.

"For now, they have given up on me in Russia," she wrote.

She collected donations online and sought treatment in Germany, where doctors said she may have been misdiagnosed because not enough examinations had been done. They said she could have been operated on and cured if her doctors hadn't missed the early stages of the disease.

Gritsai, 35, died at the Grosshadern Clinic in Munich on Oct. 22 — but apparently not from cancer. Doctors told her husband, Yevgeny, that she had been poisoned by the chemotherapy drugs Cisplatin and Xeloda, which are also used in Germany but are accompanied by supportive drug therapy to diminish harmful side effects and aid recovery.

Gritsai's case highlights many of the faults with cancer treatment in Russia's state health care system, which doctors say suffers from problematic legislation, excessive bureaucracy and a lack of financing.

Gritsai's experience, which she described online and in an interview with The Moscow Times in late September, included lying sick on the floor of the Blokhin center for hours to take a blood test, meetings with indifferent doctors and attempts to perform minor surgery with no anesthetic.

After Gritsai received the grim diagnosis from the Blokhin Center, her husband found a doctor at the clinic who prescribed chemotherapy treatments for Maria "at his own risk." The treatments were performed at Gritsai's home by a local doctor, she said at her home in Chekhov, a Moscow region town 60 kilometers south of the capital.

Gritsai spoke briskly while sitting on a stool in the kitchen of her three-room apartment, her eyes lively despite a pale face. Plastic bags hung on her hips attached to 5-millimeter plastic tubes, which she had to have surgically installed after her kidneys failed.

In a public appeal she wrote online, Gritsai wrote that after each of seven chemotherapy sessions, she felt so bad that she could only lie in bed for a week sleeping, throwing up, drinking water and eating nothing.

She wrote that she was put on disability and given monthly payments of 7,000 rubles (\$220).

"I have no right to die. I have endured too much," Gritsai wrote. "I will live to give hope to allegedly hopeless patients."

Deadly Delays

Cancer treatment is free of charge under Russian law, but patients often have to wait weeks or months to receive drugs or undergo medical exams, Gritsai said, speaking from her own experience at the Blokhin Center and at a local clinic.

Alexander Nikolayev, head physician at the Blokhin Center, said that in many cases, state financing is insufficient to provide high-tech care to cancer patients and that hospitals and patients struggle to collect money for treatment.

Since January, a law titled "On the Basics of Health Care" has limited the amount of free medical services to which people are entitled. The amount of free services is defined by a government program <u>each year</u>.

At the same time, Russia remains the only country in Europe where patients don't pay for obligatory medical insurance, Larisa Popovich, director of the Institute of Healthcare Economics at the Higher School of Economics, said at a round table last year.

The Blokhin Center provides free treatment to Russian patients, who receive referrals from their district hospitals as part of an annual state quota for treating patients with high-tech medical aid. Foreign patients must pay for care.

The state quota cannot cover all patients who need care, and state money for treatment at the Blokhin Center is allocated only after a patient's diagnosis has been confirmed there. As a result, patients have to pay for all the tests, consultations and examinations before that, patients at the center said.

Gritsai said she and her husband repeatedly arrived at the Blokhin Center clinic by 5 a.m., three hours before it opened, to get in line for a blood test with about 200 other patients. Some patients spent the night in cars beside the clinic to get a test before the laboratory closed, Gritsai said.

The Blokhin Center offers paid medical tests along with the free ones for patients covered by the state quota. Paying patients have to stand in the same long line, but the results of their tests arrive sooner, Gritsai said.

In October 2011, the Investigative Committee opened an inquiry based on a tabloid <u>news</u> <u>report</u> in connection with the death of a woman who had been waiting in line at a doctor's office at the Blokhin Center. The results of the inquiry have never been publicly reported.

It took Gritsai a month to undergo all the necessary tests and exams before doctors at the Blokhin Center made their diagnosis, Yevgeny Gritsai said. That was a critical delay given that a malignant tumor can advance considerably in just a few days.

Yevgeny Gritsai said doctors at the Grosshadern Clinic could have performed more tests and made a more precise diagnosis in a shorter period, 10 days.

On one morning in mid-November, about 25 people were standing in line for blood tests at the Blokhin Center. An elderly female patient told a reporter that the line is bigger on some days, but she also praised the "quick and clear-cut organization" of consultations, tests and examinations, saying results of blood tests were almost always ready the next day.

A 40-year-old male patient who spoke by telephone said he spent a month confirming he had a malignant tumor through paid tests and examinations at the Blokhin Center. He was then told he could wait four months for a free CT scan or pay for the exam and undergo it sooner.

At the same time, an Israeli clinic the patient consulted told him it could have his diagnosis within a week.

The man, who spoke on condition of anonymity because he might have to return to the Blokhin Center for treatment, complained that doctors there were "rude" and "never explained anything" to the patients.

He also said he spent hours in line at the doctor's office every time he needed another referral for an exam or a test to obtain a diagnosis.

Struggles to Get Medicine

By law, authorities must provide free medication to gravely ill patients within 10 days of receiving a prescription, but Gritsai was told she would need to wait four months for the hormone erythropoietin, or EPO, which a doctor said she needed to treat the anemia that resulted when her kidneys failed.

Faced with such long waits, relatives of fatally ill cancer patients often try to buy the drugs on their own. But the prices can be steep: Gritsai said drugs containing erythropoietin cost 80,000 rubles per month for the dose she needed, or more than 10 times her monthly disability payment.

Patients can find it difficult to get a prescription for a powerful drug from a doctor because several stamps from different people are required on the prescription, and doctors can be reluctant to go through all the trouble if they are overloaded with work, especially if a patient seems unlikely to make a full recovery.

When Yevgeny Gritsai tried to get a prescription for the chemotherapy drug Xeloda from a local oncologist, she told him, "Why spend your money on Maria? She is going to die anyway. Meanwhile, I have a lot of work," Yevgeny Gritsai said. He asked for the doctor's name not to be published to avoid causing problems with her.

To give Yevgeny Gritsai the prescription, stamps of approval had to be put on it separately by the head of the gynecological department at the local clinic, by a commission of doctors and by local health authorities.

Problems also plague some of the medications themselves. The chemotherapy drugs used in the state medical system are cheap and often have harsh side effects that can kill a patient rather than eliminating the cancer.

When Xeloda and Cisplatin are used abroad, a course of powerful supportive therapy often accompanies the treatment to offset their side effects.

According to its label, Cisplatin can destroy the kidneys and may have side effects on the

digestive, cardiovascular and central nervous systems, blood production, metabolism and reproduction and may cause allergic reactions. Xeloda can cause a range of similar and other side effects.

Of the side effects described on the labels of Cisplatin and Xeloda, Gritsai had anemia resulting from kidney failure and a mycotic infection in her lungs.

According to Yevgeny Gritsai, his wife's doctors at the Grosshadern Clinic told him she had died from the poisonous effects of these drugs, though this information could not be confirmed.

A spokesman at the Grosshadern Clinic refused to comment on the details of Gritsai's treatment, citing local regulations protecting patients' privacy, while Yevgeny Gritsai said he did not take any medical documents from the clinic after his wife's death.

Anatoly Makhson, Moscow's top oncologist and the head doctor at the city-financed Oncology Hospital No. 62, complained that his hospital was forced to buy cheap, Russian-produced generics for chemotherapy that have potentially dangerous side effects.

Makhson was referring to amendments to the 2005 <u>law</u> on state purchases signed by President Vladimir Putin in July that bar state medical institutions from buying brandname drugs.

"Imagine you are given a drug that costs 8 percent of the price of a normal drug," Makhson said. "Often, patients start taking them [but] tolerate them badly and give them up."

An inquiry submitted to the Health Ministry by e-mail in early October regarding the amount of budget spending for cancer treatment and the reasons for delays in drug supplies went unanswered by press time.

A spokeswoman at the ministry said several times over an eight-week span that she was busy replying to other media inquiries.

Dispensing Pessimism

Gritsai said she considered one of the worst aspects of Russian cancer treatment to be the pessimism it instilled in many patients.

Those who have no money for treatment abroad and lack the will to endure the side effects of the cheap chemotherapy "give up, lie down on a sofa at home and wait for death," Gritsai said, citing conversations with other cancer patients.

"The most horrible thing is that people give up on themselves. Cancer is not a death sentence," she said, adding that she thought a free psychological service specifically for cancer patients would be in demand in Russia.

In October 2011, Russian doctors predicted that Maria would live another two to three months. Instead, she lived for almost a year.

Coping With Cancer:

- Desperate Patients Seek Care Abroad
- <u>Russians Show Generosity to Sick Compatriots</u>

Original url:

https://www.themoscowtimes.com/2012/12/16/coping-with-cancer-patients-struggle-in-faulty-state-sys tem-a20256