LETTERS FROM THE LAND OF FEAR

Intimacy, Beauty and Death in Central Asia
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Calvin White
She’s no longer in the TB ward, the cold bare walls painted a peeling yellow, the heat from one lone wood stove several rooms away. There are no other patients lounging nearby wondering what this odd foreigner has to say to them, amidst their boredom in the village sanatorium. There are no echoes in this room where the 22-year-old in the swaddled, traditional dress is not smiling and exchanging laughter as she was just two weeks before.

She doesn’t have the multi-drug resistant strain of tuberculosis, only the regular TB. Only. It will kill her just as surely, but the medical regimen she needs to follow to prevent that early death, the relentless disappearance of lungs, is not so arduous. Just two drugs that are barely noticeable to her system. But every day for three or four months.

We are in her home seated on mats across from her. My translator, me and this sweet-faced girl who stares at the floor more often than she looks at me. She has stopped the medicine. Her grandfather has come to the sanatorium and taken her home. He came with another old man, and together they did their own treatment on her. Don’t take those drugs anymore. They won’t work. We will cure you our way.

What was she supposed to say? What could she do? They walked her home and had her face the wall. Then, as they spoke strange sounds, they struck her over and over on the back with a long stick. Whump! Whump! Whump! That’s how to bring the disease out. How to chase away its cause.

She looks at me trying to smile, a quiet confidence. A quiet resignation clothed in a familial duty of hope. In this country, despite its
outward modernity, its ubiquitous cell phones, and its Russian legacy, the ways of the past are still the ways when they want to be. A shaman is a shaman. The evil eye is real. And what are the Western TB drugs but other kinds of inner sticks beating from the inside? She now beats her own back three times a day.

I look at her and nod. Your grandfather is wise. You can keep doing his cure. But he doesn't fully understand this disease. I do. You must start taking the drugs again and do both cures. If you do both cures, then you will become healed, become well enough. I smile and nod, looking her in the eyes.

She smiles and agrees. I'm a good liar.

For 11 months in 2010, I undertook a mission with the Nobel Peace Prize-winning international humanitarian organization, Médecins Sans Frontières (MSF), known in English as Doctors Without Borders. I went to Uzbekistan in central Asia to work as a mental health specialist with the MSF team there to address an epidemic of multi-drug resistant tuberculosis.

Little did I know that such a nonedescript role actually meant emergency counselling. It was as though, each day, a human being was placed on a ledge ten stories high and I had to talk them out of jumping. They hadn't chosen to go there, but they were definitely thinking of jumping and it was up to me to search out some rationale, some aspect in their lives, or some convincing bit of hope that could bring them off the ledge, at least for that day. And I had only minutes to do it because there were a whole bunch of others on other ledges that I had to get to.

If I couldn't find the right words, couldn't understand clearly enough what they needed to hear, couldn't connect with them deeply enough, then they jumped. Not the quick plummet to instant death, but a slow fall of days or weeks to a death just as sure and in some ways sadder and more far reaching.

So, I became a negotiator, and each case was different. Sometimes, I could see them ease away from the edge. Other times, I’d have to leave knowing they were teetering. I’d have to close my eyes and hope

In the 1960s the Soviet Union decided that cotton could be a major cash crop in its Central Asian Republics. That area is very arid so the need for constant irrigation was obvious but not deemed to be a problem. Two major rivers traversed the region and they could be dammed, diverted, and exploited to flood vast swaths of land for the cotton. And cotton, indeed, did grow and the area became a world player in cotton exportation. They termed it “white gold”. After the Soviet Union fell, an independent Uzbekistan morphed into its current autocratic rule and the cotton production continued, the irrigation continued.

But, as is often the case, other consequences followed. The rivers, Amu Darya and Syr Darya, were the only water source for the Aral Sea. When the rivers were so drastically drained, the Aral Sea began to shrink. It has continued to shrink to this day and the whole scenario is now infamously known as the Aral Sea Disaster. It is an unprecedented global disaster because the Aral Sea was not just some innocuous body of water. It was the world’s fourth largest body of inland water. For thousands of years it was the living constant for the inhabitants of the region. And then, in a generation, everything changed.

The southern half of the Aral Sea is in Uzbekistan and more precisely in Karakalpakstan, which is nominally an autonomous region in the west of that former Soviet republic. The Karakalpaks have borne the true effects of the Aral Sea’s demise. When the waters shrank, an
immense sea bed of salt was exposed along with pesticides and all manner of toxins deposited over the centuries. In this desert landscape, the winds carried the poison-laden dust for hundreds of kilometres in every direction. The health of the population began to deteriorate.

At the same time, all the economic and social benefits of this fishing and tourist habitat ended. The water of the Aral Sea, having become so salt concentrated, no longer sustained fish species. A poor population became even more impoverished.

In 1997, MSF came to the region in the belief that the environmental degradation had to be causing severe health problems. Indeed, it was. MSF realized that tuberculosis was prevalent in epidemic proportions. The organization began working in collaboration with the Uzbek health ministry to implement the World Health Organization recommendations for TB treatment and control. By 2001, MSF could see that the regular TB epidemic had escalated to a more alarming situation. It was clear that Karakalpakstan was in the midst of an epidemic of multi-drug resistant TB (MDR-TB). The tuberculosis bacillus was transforming. When people with regular TB don’t complete their treatment or take the wrong treatment, the risk of the bacillus becoming a super bug increases. That means the normal drugs no longer work. When those already with multi-drug resistant TB prematurely stop treatment, it can lead to extreme drug resistance (XDR-TB) and the prognosis for cure is minimal.

Tuberculosis is a poor person’s disease. It stopped being a concern in the developed world decades ago. Improved nutrition, education, health services, and the general material well-being of Western societies are responsible for that. But worldwide it is estimated that one third of all people are infected with the regular TB bacillus, though of these only a tiny percentage develop the active disease and need drug intervention. Active tuberculosis seems to be an immune system illness. When the immune system is compromised or at risk, the TB bacteria becomes active and symptoms develop. As an airborne disease, infection happens by being coughed, sneezed, or breathed on.

Because TB is a poor person’s disease, the drugs used in its treatment are largely the same ones used in the 1950s when Western nations were also afflicted. There has not been the financial incentive for research to develop new drugs. To treat MDR-TB, patients must take more drugs and for a much longer time, and all of these drugs are of the same 1950s’ vintage—and have toxic effects on the body. These side effects are the biggest obstacle to patients adhering to the full duration of treatment.

So it was that, in early February of 2010, I ended up in Nukus, the capital of Karakalpakstan in western Uzbekistan to work with 450 patients suffering from MDR and XDR-TB. I knew nothing about disease, nothing about TB or MDR-TB, and nothing about Uzbekistan. Like everyone else on the planet, I had never heard of Karakalpakstan. In fact, it took me a month to be able to pronounce the word correctly—after all, it does have five syllables.

I never really lived in the space that I physically inhabited. I lived within the reality of those hundreds of Karakalpaks who fought one of the world’s most terrible diseases. Very early in my time there, I realized I was each day immersed in the human heartbeat. Culture, language, gender, and age all disappeared.

MDR-TB is a killer. Though it can attack other parts of the body, most often it is lungs which are ravaged. Slowly but persistently the bacilli destroy. There is no guarantee that the massive amount of drugs will even work. But everyone starts with hope. Thus, this is a story about living and living with hope. It is a story about dying. And in both cases it is a testimony to a population which struggles each day to make the best of its breath. It is a story of intimacy. It is a story about beauty.
Imagine you are being swept along in the slow waters of a great river. Every so often a fleck of gold surfaces and catches your eye as it glints in the sunlight. Then it sinks again into the depth or floats beyond your sight. Occasionally one keeps its direction near you for some time. The wonder of all that. There and gone, but bright and textured, the brilliance there for you to see. And if each of these individual flecks had a name, you would say that name, but then forget. You would only remember those who stayed longest. But all, all would remain the gold they really were. And then you would be left to whisper: “What a river. What a great river.”

It is the end of January 2010 and I’m on a plane from Kelowna to Calgary to Frankfurt to Moscow to Tashkent. Twelve hours away to the other side of the planet to Uzbekistan, one of the five stans from the former Soviet Union, now a stan on its own run by the same guy who ran it under the Soviets: Islam Karimov. Like probably every other westerner I had only heard the word Uzbekistan and knew it was over there some place. On the map, I had seen that my project was located in a city called Nukus in the west of the country. It was close to the Aral Sea. I was happy. The Aral Sea. Wow! A long way from Silver Creek where I live. I can’t wait to see it. The fourth largest body of inland water in the world. Only the Caspian Sea, Lake Superior and Lake Victoria are larger. Wow!
Below us suddenly are thousands of glowing spheres. The phosphorescence of a tropical sea suddenly reborn instead as gathered eyes searching upwards from this land of central Asia.

When we land at the Tashkent airport, everyone claps. I climb down the stairs from the back of my plane and cross the tarmac to the bus. It is a frosty, still night with a full moon. And it suddenly sinks in that I am walking in the centre of Asia. Marco Polo’s route.

**Tashkent, January 30**

It’s cold but not too bad. I wear my t-shirt. I walk to the MSF office. It is afternoon already. I am 12 hours different from where I last woke up. I am walking upside down. The sidewalk feels the same. This is another big city. Small cars whiz by on the two lane street. Big trees are on its edges. A drainage ditch separates me from the road. No one pays any attention to me. Some men wear dark fur hats. I am in Central Asia. This is it.

I am badly jet-lagged, having only slept intermittently in the MSF Guest House, an immaculately appointed, warm, two story house within a groomed, locked courtyard. And now only a few hundred metres away I walk through the metal doors to the MSF headquarters.

Everyone is friendly, if not especially interested. The financial officer gives me a big wad of money. The currency is called sum — pronounced som. A 1000 sum note equals half a dollar. I am informed that my HIV test is useless. It needed to be stamped and signed by a Canadian doctor. Unbeknownst to me. It might have been helpful to tell me in the first place exactly what documentation was needed. At any rate it should not surprise me. I just hope they get on my missing bag that never arrived on the plane with me. The guy that the job was given to says he’ll check it out tomorrow. I say that I might be leaving for Nukus tomorrow. “Oh we’ll check today then.”

I meet Stefan, the head of mission — HOM. All of MSF is abbreviations and shortened forms. I’m MHO — mental health officer. Stefan seems like a good guy. A Norwegian who has a PhD in Sanskrit, he stays here with his wife and two young daughters. Today is his day off and he has only come in to say hello. He tells me Nukus is quite a safe place to be, likely because all fear the police and the state authority. I can’t tell if his large eyes are because he is open and friendly or because he is uncertain about me. I learned earlier that I was not the first choice as new mental health officer.

Next, it’s into another office for the meeting with the Medco, the MSF medical coordinator for all medical activities in the country. Jorge is the Medco. He has dreadlocks. Big guy, Spanish, tells stories about missions in Africa and India and Moldova. He seems surprised when I ask a question about TB, mentioning that I know nothing about the disease. He says, eyes big with surprise: “You don’t? And then: “What diseases have you worked with?”

I respond: “None.” His eyes get even bigger.

I know this much: MDR-TB stands for multi-drug resistant tuberculosis, meaning the regular TB bacteria has mutated to become resistant to many of the basic TB fighting drugs and that the afflicted person is in shit. I know also that my job is to be the mental health expert who will lead a team of local counsellors working for MSF, trying to keep MDR-TB afflicted patients on their drug regimen. This drug regimen will save their lives. If they stop, then the bacteria might become more resistant. Each time a patient stops taking the drug regimen the epidemic worsens, the patient likely dies, and the people around the patient can become infected.

The Medco tells me the drugs are quite terrible. They are the same drugs developed in the 1950s and they cause rather awful side effects. Nausea. Headache. And worse. That, since they have to be taken every day for two years, the patients often would like to refuse the treatment. Unlike the case with cancer chemotherapy though, if the patient opts for no drugs and no terrible side effects, it means they infect others. It’s my job to get them on treatment and, once on, decrease the level of defaulting. I’m replacing an American PhD who has been here two years and who set up a good system but has now finished her mission.
I walked to the bazaar yesterday — about three kilometres. It was cold but not as cold as in Canada. I’d say about 6 below Celsius, dipping to 11 below when the wind rose. The bazaar is the main market place. Much is outdoors or in small shops and then one big central venue with tables set up. But no heat anywhere. I don’t understand the language, either spoken or written. The alphabet is not like ours. So I couldn’t tell what was what. I did manage to get cheese, bread, some cookies, walnuts and a jar of strawberry jam. I point and then hold out my wad of money for them to take what I owe. As far as I could tell, they don’t try to rip you off.

Speaking of money, the highest bill is 1000 sum which equals half a U.S. dollar. So everyone has to carry this big wad of bills to pay. And there are no coins.

We aren’t allowed to take public transport so, every time we want to go out, we get a chauffeured MSF car if available. Or we can walk. In other seasons some bikes are available. Not much traffic here so it’s pleasant to get around. In the residential areas, the houses are low style, squarish, featureless and fronted by a wall. All you see are entrance doors. Then into courtyards and then the dwelling. Nothing like a country in south or southeast Asia with its constant visual stimulation.

The crows huddle in dark clumps on the bare branches. The desert cold sticks to them. Twenty below zero to a crow must seem much like it does to a human. Their beaks are hidden beneath tightly folded wings, pretending the vulnerability to freezing fingers of this wind doesn’t exist.

These are the wise birds of Karakalpakstan. Aziz, my 30-year-old senior counsellor, tells me they can live to be 100. But he doesn’t like them, their parallel lives unreachable, unlike the dogs with whom Karakalpaks have formed a working relationship. He knows they must be wise, the keepers of how it is, how it’s been, seen it all but never sharing any advice, as they hop on the ground with less impudence than the magpies but too much self-assurance. He’s seen one suddenly die, fall stiff onto the ground. Seen others with beaks cracked with age. He doesn’t like how they huddle in the trees like dark winter fruit which no one would ever want to eat.

I am a foreigner, another expat with MSF. Thirteen years of revolving door expats all arriving and departing, from many different countries. Manas has seen them all. He’s been a guard in Nukus for 12 of those years. He sits at his 15-hour shift — 6 am to 9 pm — ready to answer phones, send cars for needy expats, answer the doorbell to allow someone in. Long shifts. Good pay. Manas has eyes that burn into you. He studies expats, harbours deep cuts. He teaches aikido, urges me to join his class. Maybe I will. At least, I’ve actually heard of aikido, and it will take me out of my norms. Might as well go all the way in that department.

I am a foreigner. For the Karakalpaks who work for MSF, the drivers, the cooks, the logisticians, education planners, guards, assistants and translators — referred to as National Staff, we are diversions, something to add a bit of interest. Whenever a new one arrives, at their first lunch in the main MSF building when all eat together, the expat is introduced and asked to say a few words. When it’s my turn, to add some levity, I give myself a female name and claim to be a former lover from a past life of the cute Kyrgyz expat doctor. Everyone laughs. I want them to see me as a bit strange. It will make my life easier if they expect non-normalcy.

Then we eat. Two long tables, plates of salad, bread wheels, peanuts in the shell, cookies, a fruit, large common dishes of rice plov, or dumplings, tea, and the contented cackle of chewing teeth. Each work day at 1 pm, Gulya, one of the cooks, will holler: “Lunch!!!” And all 53 of us expats and locals crush against each other to get to the table with the biggest bowl of fruit.

Just a few years after my brother was born, my mother was diagnosed with tuberculosis. Treatment and a cure meant many weeks in a sanatorium. This was a time when it wasn’t so unusual for Canadians to contract that dreaded disease. Because she was put on heavy doses of sulfa drugs, my mother believed she would never be able to have
any more children. So, years later it was a big surprise when she became pregnant with me.

It is a rich irony that, just a few months before the same age my mother was when she died from cancer, here I am on the other side of the world in the forgotten country of Uzbekistan working with TB patients. Not just ordinary TB but the new age kind which resists my mother’s drugs.

The team of counsellors I supervise has the job of convincing and supporting patients to stay on the treatment that can save their lives. This means two years of medication, often with serious side effects such as continual nausea, head and joint pain, and sometimes much worse: hearing loss, mood shifts, tinnitus, liver or kidney damage, disturbed thinking, or psychosis. In the end, there is no guarantee of success.

I understand now that the counselling part of the MSF project is really the crucial missing link. The doctors and nurses administer the treatment regimen, but if the patients won’t accept it then everything breaks down. Reaching inside the psyches of those afflicted, educating, bolstering their resolve, and solving the riddle of why some stop are the only ways to stem the epidemic. Nurses and doctors don’t do that. Counselling is not in anyone’s consciousness here. It does not exist in Uzbekistan. MSF has brought it, and even the MSF people don’t really understand it.

This is a country where respiratory disease contributes to almost 50% of deaths. It is epidemic. Regular TB is epidemic. MDR-TB is epidemic. And it will spread.

The Aral Sea—once the 4th largest inland body of water in the world, larger than all the Great Lakes other than Superior—was abundant with marine life. It supported a thriving fishing industry that fed hundreds of thousands, and attracted tourists to its picturesque shores.

But, by some estimates, it has dropped to 20% of its size. Every living thing died because the salt content became so high. The exposed sea bed, now a vast and barren plain, offers up millions of tons of fertilizers, pesticides, salts, and other contaminants to the winds throughout the year. There are high rates of birth abnormalities, more than triple the norm. Soon after leaving the station in the capital of Tashkent, 800 kilometres from Nukus, the train starts to cut through flat, arid land and a light skim of white appears. Since it was winter when I arrived, I thought it was skiff of snow. But it is salt.

Despite being a long way from the Aral Sea, salt covers the land. People here talk of the taste of salt in vegetables and fruit. Drinking water in Nukus, over two hundred kilometres from the old sea, has a slight tinge of salt. Being here and seeing the salt layering the earth around me indelibly drives home the depth of the environmental carnage.

I had learned of the situation before coming. But it was travelling across the land and seeing the white of the salt everywhere that drove it home. Each day, when I am driven in the Landcruiser away from town, I look out at the barren, flat land. It is all white. In town, bare lots are white. I think of it as the colour of tuberculosis.
Masks

I don’t really know what to do or what I am doing. My own personal life is as comfortable as it can get. My room in Vostachnaya is warm. Each day, after helping to prepare the MSF lunch, Gulya comes to clean our whole house, do the laundry, iron our clothes, even wash our dishes. Clean towels, sheets, face and laundry soap provided. Cars will take us everywhere we want to go. Someone buys food for us at the bazaar if we request it. How could it be easier? But the reason I am here and how to fulfill it is another matter.

Twice a week, I go to the main MDR-TB hospital called TB2 which was set up through the efforts of MSF. It is 19 kilometres to the north of Nukus far off the highway in the desert. I ride in the car sitting inside my skin, yet outside my skin, alien to my self. I am swept along, to walk and talk as though I am present and real. But I am still in shock, pretending to know something that matters about a disease reality with which I’ve never remotely been familiar.

When our car arrives, I am swept across the paved walkway behind the main buildings through the metal door into the back of the hospital—just where patients pass in order to go to the squat toilets or take a shower. There are two wards. The first is a long concrete hallway of rooms where the new arrivals reside until the medication reduces their infectiousness. It houses up to 40 patients. These patients have a small kitchen in which to cook food before returning to eat in their own sparse rooms. That wing connects to the less infectious two-story wing which has a high ceiled foyer area and a large lunchroom with floor-to-ceiling windows. In the foyer a tree with
rooms with up to eight patients, two small, refurbished kitchens for the patients, nice bathrooms. The second floor situation is easily the best condition in this rambling TB hospital. The bottom floor is for patients who are slightly less drug resistant. Their floor is dingy, practically basement fare. I guess MSF didn’t have enough money to remake both floors.

TB2 is outside town. It’s all MDR-TB with some XDR patients. It’s actually a pretty peaceful place. On entry through the gates, the front is roughly landscaped with trees, some shrubbery, sitting areas. Its spartan concrete halls and rooms are not so bad — bare, but clean and habitable. Each of the two wards has its own common area for the patients to watch TV and socialize.

I am at TB2 this morning, sitting on a bed with 25-year-old Saper-buy. He’s only two weeks into treatment and scared. He comes from Karauziak, a village an hour plus away from Nukus. Two weeks into treatment. Only 102 to go. He has missed his pills the last few days, the twenty ovals and oblongs he will have to take these 102 weeks, six of every seven days. He’s refused his injection, the needle that is to jab into his upper buttock six days out of seven for at least another year. He did take his drugs today though, and now he is nauseous. But he wants to ask me something.

He has called me into his room to sit with him on his bed. He bows his head in hesitation. Then he looks me in the eyes, looks over at my translator. He tells me he got married four months before. Now he feels like he is married to this room, its four other cots, the strangers he has been placed with. He wants to go to his wife. He is new to the hospital, his mouth and nose are covered with a surgical mask, and still doing what the doctors told him to control infection when he was first admitted. I only see his eyes. He is scared. He tells me he has night sweats. How long will it last? Is it bad? I say I don’t know, that I will ask the doctors and get back to him.

Then he says what he really wants to ask. He wants to know if he can go home to see his wife or if she can come to see him. He wants to know if he can have sex with her. I tell him there is only danger if he breathes on her. I ask if his penis breathes. He doesn’t get the joke and thinks I mean does it get erect or not.

His life has become not what he thought it would be four months after the day he danced with a bride in a flowing white dress, drank the long line of vodka toasts to every expression of good wishes for their future happiness.

February 26

She died
the grimacing beauty
She was sent home
to die

I wanted to see her again, but we had gone on a team building retreat to the mountains. I wanted to show her that the first meeting was only a first meeting. Or if I could see it was ending, I could have held her hand good-bye. But I had been too late in saying hello. And I really would have danced with her. Now she dances lighter than a single faint crystal of snow. Lighter than that.

Aizada.

February 27

There are ten women in this room. By coincidence it’s room 10, the biggest in TB2. Being in the same room means having similar drug resistances. After a couple of months, the lab tells which drugs the patients are resistant to and what their bacteria count is which suggests the degree of infectiousness. These women are in the second ward of TB2, the two-story side, which means they are less infectious. They have told me they want to talk. I came back to see them because during doctors’ rounds I had gone to each to shake hands and say salaam alaikum and the older one in the corner had gripped my hand firmly and looked me deeply in the eyes. Now, I have come back to know the others.
I sit on the floor against the wall beneath the windows and look out at them as they sit on their beds staring back at me. They are smiling. The foreigner has come back to see them. To talk with them. They want to know why no one else ever does that. I say I don’t know. They ask what I am? I say, a human being. They say, of course we know that but what are you? Are you a doctor? I say, I am a human being. They laugh. Then they want to know about my country, its climate, my family, my age, my salary, the length of my stay in Nukus.

We talk and then I ask about them. I say that I’d like to know something of their lives, their family, when they got MDR-TB. A young woman, who has been lying on her bed in obvious discomfort, says she will start. She has her usual splitting headache after taking the drugs. She is nauseous and her whole body aches, but she sits up to tell me her story. Her face is ivory, eyes almost blue, muted orange-brown cloth bandana wrapped around her head, traditional housecoat. She speaks slowly, pausing to let the truth of each revelation sit in the hollow air of this room 10, with the foreigner who wants to know what too many here want to forget.

“My name is Gulshat. I am 26 and I have two daughters, two and five.” Pause. “I got MDR-TB five months ago and came to TB2 in November.” Pause. “My mother died from MDR-TB in 2007. It was difficult. I attended to her every day, wishing her to gain strength. Wishing for the coughing to end. Her face to fatten. Her laugh to return.” Pause. “My father died from it in 2008. He never recovered from my mother’s death. His heart was broken. His lungs became broken.” Pause. “Two of my sisters died from it in 2009. We tried everything we knew to save them. They were younger than me. I loved them so much.” Pause. “So, there is lots of sadness in my life.” Pause. “I want to be cured for my children’s sake.”

I stop her there. One of the other women is crying. The room is silent. The spoken words have shattered the nausea, shattered the illusion of being safe in solidarity in this routinized hospital room. I am astounded. I cannot imagine Gulshat’s loss. I say that I don’t want to continue talking as though her great tragedy is just another anecdote, that we need to sit with it a while, honour her truth. Sit in some silence and just be. Later, I say I need to leave, that I will come again on another day and hear other stories.

How many will be like this?

I am learning. There are cockroaches in this house called Vostachnaya. Longish, brownish, lots of legs. I think they are cockroaches. They seem to have lots of legs. They like the bathroom and kitchen the best. In the morning, I’ll find one trapped in the bathtub, its steep, inclined walls with their slippery enamel. I’ll stick in a plastic container for the cockroach to skitter onto and transport him to a more liberating environment. He or she gets out of the light and exposure as quickly as he or she detects a hiding place. I don’t know why people dislike cockroaches. What did they ever do to us?

We have a project team meeting each Monday at 4 pm. PT meeting, it’s called. All the MSF expats gather to exchange their news, plans, and requests. I have learned to measure what I say, how I say it. Better not too much information or else a need for explanation. Or worse, justification. I can’t explain. I don’t like to justify. I’ve just come here to do. I have been working directly with the patients. Nine to six each day, talking with them, knowing their reality, holding them sometimes. I call it giving energy. Sick people often perk up if someone says they have energy to give. Whatever that really means. I’m not going to tell the other expats that I hold patients. Hold them for a full one to two minutes. Letting our realities communicate without words, letting our breathing move together, our hearts beat together. Allowing culture to disappear, age, gender, language transform to being. Being together. My counsellors, the nine left by my predecessor, think I’m odd. Say that their people don’t touch like that. Men don’t hold women. Even a husband and wife if they haven’t seen each other for a week and meet on the street won’t touch like that.

I’ll just mention starting a weekly newsletter, say: ‘I’m learning. All is well. Is there a way of getting a heater put into the counselling room in Chimbay? And, we have no room to counsel in, no privacy,
March 2

Today is the first day of work for my new translator and assistant. Her name is Aynur. She is 29 and has dimples when she smiles. Before I arrived, Jenny had hired her for the future because she thought it would work better for me as a male to have a female translator. Her previous assistant was scheduled to become solely the transportation manager. But our Project Coordinator had been on holidays so the official job start couldn’t take place until today. They had wanted me to meet her first anyway, make sure we fit. Someone mentioned they had heard that Aynur’s husband was National Security, Uzbekistan’s secret police. They wondered if maybe she was being sent as an informer.

When we first met, I could see that her English was very good. She looked right at me. And when I told her how we’d be doing therapy, doing whatever it took to help patients, she nodded. Then I spoke about counselling patients who had been raped or suffered sexual abuse. Her eyes became emotional, but she still nodded. The advertisement had said the job was mainly office work with lots of written translation. Unexpectedly, I was telling her we’d be going into a fire each day.

I have just told her that up to now I had been using Jenny’s previous translator, Aziz, Altinay, and my young English-speaking counsellor, Deelya, for translators and that they had allowed me to get to know some patients, become familiar with hospitals, clinics and routines.
KGB became National Security. Everyone understands that they are not safe unless they follow the rules, stay away from controversy.

In Karakalpakstan there is virtually no literature or writing of any kind being written and none being read. It costs money to publish and everything must be first vetted by the security offices. With television so prevalent, reading for pleasure, stimulation, or learning is not necessary. In Soviet times, there was access to and interaction with Russian literature and Russian writing. During the past twenty years of the post-Soviet era, the use of Russian has diminished drastically. There are no book stores in Karakalpakstan. At the used bazaar, a few stalls sell piles of old books. Tabloid “newspapers” are fluff. Yet, the large statue erected in the centre of the expanse of greenery and fountains that front the President of Karakalpakstan’s huge palace is of Berdakh, the 19th century Karakalpak poet. And everyone speaks fondly and respectfully of Berdakh.

Many Karakalpaks believe they have historically been discriminated against by the Uzbek authorities. It is said that a much higher ratio of Karakalpaks than Uzbeks were sent into the Second World War. How favouritism started in the east of the country and never reached the west. The Aral Sea disaster has piggy-backed on the fear. Everyone understands how their health and the health of their children has been impacted. No one is surprised to develop a disease.
Counsellor joking with Deena and Gulsara at TB2 during a concert day. (Photo courtesy of Marcell Nimfühl)
Islam and the author at TB2

Slohan on a happy day at TB2
Moments in the Sun

May 10

When I visit Kurbangul and Gulbasara in ICU they always teach me about the possible. Gulbasara has been on her bed in ICU for more than four months. She has a sponge mat to place under her hips to counter bedsores. Her MDR-TB is in the back, lungs and left eye. Kurbangul, though only 26, looks much older. Both are thin. Bones within skin. Neither can walk, though Kurbangul is very agile and can fold and unfold herself into various positions on the bed.

I was the counsellor who first told Kurbangul that she had MDR-TB and that it meant months in hospital and two years of daily treatment with toxic drugs that cause dire side effects. Her face contorted with shock, and after stunned silence she smiled and said she would just have to be strong. Now, when I come to our hospital and enter her room, she stretches out her stick-like arms to me and pulls me to her for a long embrace. When we finish the embrace, I kiss her through my mask on her cheek. Neither of us can speak the other's language, and of course our cultures and upbringing are radically different, but we communicate fully. When the nurse or doctor see our long embrace, they can't figure it out.

Gulbasara is a different story. After we began to talk, I was always curious to find out what new musing or state I would get. Philosophical, fearful, disconsolate, energized? Could be anything. Every so often, her father and uncle would visit and I’d see them propping her up one to each arm and helping her walk the ten steps back and forth in the little aisle that fronts the three ICU cells.
One day, I was visiting as she was preparing some food for herself. Unlike Kurbangul who can easily move around on the bed, Gulbasara lies mainly flat on a very slight incline from a heightened pillow. She had a tomato and a cucumber beside her on the bed, having plucked them from her small bed table. In her hand was a paring knife and a cup just a bit larger than the normal one for tea. She began to slice the two vegetables. She had to look downward along her cheeks to see properly. The slicing was meticulous. One piece. Then a half. Then into quarters. The tomato got done. Then on to the small cucumber. She was making a salad. I had to hold back from grabbing the knife and doing it for her. Allow her this power and witness it, how painstakingly slowly the cucumber was sliced. Then just as slowly, she reached over for a small plastic bag on the table. She untied it. Salt. She sifted some onto the salad. Then with the knife she stirred it. All from the prone position she had been in for all these months.

Fifteen days ago, Aziz and I took them both out in wheelchairs. They crave to be outside and breathe and interact. Kurbangul’s eyes open so widely once in the natural world. She takes everything in, examining the state of the grasses, the leaves on the trees, the clouds, the spraying of water from garden irrigation pipes. Gulbasara has long worried that she will never walk, and asked us to go farther, out of the hospital grounds compound and along the road to wind through the scrub desert pastures. We obliged. In fact, for a short distance we semi-raced the two wheelchairs. We wanted them to feel the motion, the air flowing against them, to know that they were as alive as anyone else and that we didn’t see them as limited or forgotten. We wanted to spark them. The pebbles spat up from the wheels. The two women laughed. They thought we were nuts.

About 400 metres from the hospital, we halted and watched cattle grazing. Gulbasara joked that, when she could walk, we should go out farther in the day and buy some fruit from the farmer and then go back again in the night and steal some more. The four of us spent an hour together and it was great. Two days later, even though it hadn’t been my first time doing so, the local doctors raked me over the coals for taking them out without permission, for racing them, and for going away from the hospital. Their spies are always watching. It’s the nurses’ responsibility for patients in ICU, they exclaimed. What if one of them had been hurt? Who do you think you are? You are not a doctor. Since I have to work with patients for many more months, I accepted the doctors’ remonstrations and apologized.

Then about ten days afterwards, Gulbasara started to walk by herself. Her stick thin body moving slowly, carefully step by step out to the hall, dishevelled hair, worn pink bed clothes. A few days ago, she made it up two flights of stairs to sit and watch television. When the doctor found out, she ordered Gulbasara to stop doing it. It was too risky. Gulbasara felt defeated and cried when she told me about it. But she continues to walk.

As for Kurbangul, because I am very busy, and out of hesitation at the doctors’ ire, I backed off and decided to let the hospital personnel take care of things. Now, today, fifteen days after I last took her and Gulbasara out in their wheelchairs, I ask permission and take her out again.

She loves it.

Naively, I ask when she has last been out. “When you took me out,” she replies. “You remember.”

I can’t respond.

Kurbangul’s eyes roam everywhere, and she smiles at all she sees.

May 11

Deelya and I have gone to Hodjeli to see my Guldana. We meet at the train station outside in the great, bare parking and drop-off area which would indicate a major city if we hadn’t just driven along the ordinary street to get here. The station was a hub for most places in this country until change brought cars and enough money to drive them, make money from them.

Guldana gets out of a taxi with her brother. We walk towards each other. I am excited. This is how I told her it would be three months ago. We will meet together like real humans not patient and counsellor, meet together and have a drink and sit in the sun. I remind
No more hope.

When Deelya tells me the outcome, I am devastated. I want to tear the walls down. They asked me to help him decide, but now I see it was a lie, there was no deciding. No one wants Oleg. I frantically phone Samuel. "Yeah, it was too bad. You should have been there. Deelya tried but they would not listen to her. I think if you had been there then the decision on Oleg would have been different."

I want not to be in my skin. I want to rip it off and disappear. This is too much for me. Oleg has no one. Not even me.

June 11

It is Saturday and I’ve gone with Deelya to see Oleg in his new room at TB3. I am ashamed to see him and scared. I apologize for failing him. But, of course, Oleg knows who I really am. Just another person in the big river that moves us. He was shocked to be told it was all over. He said he had cried when the doctor left. But he has resigned himself now. No more drugs. And a new place. I give him the apricot juice I have brought and the montey dumplings still warm. He bows his head.

We talk about Massor and Natasha in the other rooms, how they were sent here over a year before and are still doing fine. I say I will make sure he has enough food. I will come out to see him two or three times a week. Whenever I leave Oleg, I always bend to him, shake his white hand and touch my head to his. Today, I do it with more humility.

June 13

I’m in the middle of interviewing prospective counsellors in Ta-khtakupir. We have gone through three candidates so far. My housemate Maru, who has become Project Coordinator for this new project, insists on being the one to start each interview, talking about MSF, etc. He’s the boss. Then we take turns with the questioning. If I start to feel strongly that an applicant is not suitable, I say that I have no more questions. That’s the signal to Maru and we close off the interview.

Candidate 1: Do you know what a counsellor is? No
Do you know what TB is? Yes
Can you tell us what TB is? A disease.
What strengths can you bring to this job? I will do my best.

Candidate 2: What made you apply for this job? I need a job.
What strengths can you bring to the job? That’s for you to determine. I can’t be the one to say.

Candidate 3: Why would you like to be a counsellor? It’s better than sitting at home doing nothing.

Candidate 4 is a 21-year-old man. He is super alert. Smiling, every utterance filled with energy and enthusiasm. He needs the money. He likes people. He wants to help. He will do everything to learn and help. This would be his first job. We thank him. I tell Maru he is like
I want to acknowledge Medécins Sans Frontières. Despite our disagreements, they are an NGO that saves lives and makes a difference. We need them. My life has changed because MSF allowed me to work in Uzbekistan. I will always be grateful.

I will also always be grateful to my former wife, Jacquie Sharpe, for encouraging me to go on the mission.

Michael Mirolla, Connie McParland and Guernica Editions are why this book exists. Thank you so much.

Marcell Nimführ has graciously allowed me to use some of his fine photographs for the book and, particularly, the cover of our beautiful Deena.

Some of the essays in the book have previously been in the Ottawa Citizen and the now defunct regional B.C. magazine, NORTHof50.

All of the Karakalpak counsellors in Nukus will forever be in my heart. Thanks to Collins Kidake for being my friend in Nukus and to my sensei, Manas Daniyrov, for his help.

Although most of the names used in the text are fictitious, this book was written as a testament to bear witness to the strength and beauty of those we served in the hospitals and clinics in Karakalpakstan. As such, it is in memory of:
Venera
Oleg
Guldana
Islam
Kurbangul
Shahargul
Gulsara
Deena
Sluwhan
Kural
Gulbazar
Aşamat
Oralbay
Malika
Nietbek
Roman
Gulnaz
Ayjan
Aiybek
Aydar
Kayrat
Sarbinaż
Mukhabat
Jadra
Saule
Sayora
Bakbergen
Munavar
Tokhtagul
A former high school teacher and counsellor in Salmon Arm, British Columbia, Calvin White translated his experience developing educational and therapeutic approaches for troubled teenagers into leading a team of local counsellors in Uzbekistan, a remote corner of central Asia. As a mental health specialist for Médecins Sans Frontières, he spent a year creating therapeutic practises aimed at saving the lives of hundreds of patients suffering from multi-drug resistant tuberculosis. During this time, violent communal attacks broke out in neighboring Kyrgyzstan, so he was also sent for a month to help the victims of that crisis. White's writing background includes scores of essays and interviews that have appeared in Canada's major newspapers including the *Toronto Star* and *Globe & Mail*, a book of poetry published by Turnstone Press, and a non-fiction book entitled *The Secret Life Of Teenagers*. As well, he has written curriculum units for college level educational/counselling programs.