

REJECTED AND ABANDONED:

GLIMPSES OVER THE BEIGE PAINTED WALL.

Yuri Zelentsov

Abstract: In this article we get a unique insight into healthcare chaplaincy in Russia. The author gives us a moving personal insight into his work among children, teenagers and expectant mothers, mostly with HIV. He describes what the word 'chaplain' means to people, his daily work and experiences, the difficulties and the blessings. He concludes with a moving 'wish list' that illustrates the stark differences between Scottish and Russian experiences of healthcare.
The editors

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The Wall.

Walls have different purposes. Most commonly, they protect, hide and block away. We see the mighty walls of the Peter and Paul Fortress in St.-Petersburg and they remind us of that. These walls were built to protect the city from invaders 300 years ago, to hide the treasures of the king's family 200 years ago and to block away those who were different, those who for various reasons did not agree with the ideas of those in authority. Now these walls serve as a reminder. But there are others that do exactly the same kind of work.

The beige-painted wall.

Just as you cross the city limits. Outside it there is a busy and "buzzy" highway, cars, trucks, buses, people, huge river boats floating up and down the Neva river. Inside it is a totally different world. The beige-painted wall is indeed a protection for some of the inhabitants. Protection from the cruel and quick-to-judge. Some people want to see it as a "block away" wall. They play a very old game that you play with your child. You cover your eyes with your hands and, hey presto, you have disappeared. The same thing with a wall. The problem (someone's pain, agony, anger, loneliness, need of care and attention etc.) is behind it and if so does not exist – they say.

But it is a hiding place as well. This wall is a mighty fortress for the garden of life, for the children, who being abandoned and rejected spend their days just like flowers. They 'open up' in the morning and 'close up' for the night. Let me share with you some glimpses of these 'flowers'.

Some details

The Hospital where the Salvation Army carries out its chaplaincy work is a comparatively small facility. There are only around 120 beds there. There are 4 departments:- for abandoned babies with HIV/AIDS; for children with TB; for teenagers from all over Russia, who were infected in their early childhood in the Hospitals of our country through various medical procedures, and who now come for their therapy and routine check-ups; and for pregnant HIV+ women who have decided to keep their babies and are receiving therapy to give birth to a healthy baby (if the therapy is being delivered correctly and in time doctors can diminish the risk of virus transmission from mother to baby down to only 1%)

Who is the Chaplain?

We are all so very familiar with those words of Paul when he said "Laugh with those who laugh and cry with those who cry". It is only since having the privilege of working with HIV children and teens that I have really entered into what he meant.

I am a chaplain. The word itself is not new for Russia, though neglected after World War I when it was common for a priest to accompany the troops on the battle field. I do not know exactly the origin of the word, but I think it means a minister who provides for the spiritual needs of a congregation not based in the church (cathedral), but rather, where the people are, whether that be in the hospital, prison, armed forces, school, police department etc.

In Russia it is expected that spiritual needs are met by a priest. So when introducing myself I say that I am a chaplain (a kind of priest) , and that I am concerned about their soul and wellbeing. People usually say – you don't look like one. Well, I guess I don't! First I wear a strange looking uniform or a clown suit; second I am young (at least I think I am); and finally I am not Russian Orthodox. And I know it will sound strange, but I think that these things mentioned above help me a great deal. People do not really consider me as a "holy father" and so they carry on speaking using the same language, sharing with me not only their spiritual needs but also the joys, sorrows and dramas of their daily living.

I am not a religious person, in the sense that most people would understand that term. Not at all. Salvationists rituals (ceremonies as we call them) are only a few and are very simple and to the point. But even I had to dust out this mentoring and patronizing manor of speech and just sit down there in the patient's room and listen for a couple of hours to the story of his life up to the present. It is quite a learning experience, I can tell you, just getting a mother to express her anger and despair about the forthcoming death of her 14 year old, bright and promising daughter; or to give a family your shoulder to cry on, or just be there for the kids, doing for them whatever they want you to do. To get down to the level where they are at, become one of them, playing their games, listening to their music, stopping their fights.

And all the time keeping your heart and ears open for that precious moment when a child (or mother, for in Russia you are not allowed to talk to the child on religious matters without the parent's permission) will come to you or will ask you in to sit down on the bedside just so that they can hold your hand, just to hear you speak those words of Life that will bring them into eternity. Or to read a book, or The Book.

Or just to sit there because they know who you are, they know that in life you shared with them their ups and downs (as much as you were able to, during their stays in the Hospital) and so, on the edge of death you can do it too.

I have to admit that it is not always my words, my witness, that make the difference. I don't think it is needed. Children are better saints than the best of us, I think.

What I do

My daily routine goes like this. I have to travel for two hours to get to the hospital. That gives me some time to read. Someone suggested that I should read a book by Elisabeth Kubler-Ross entitled 'On death and dying'. I devoured it, and asked some friends to find me more of her books. And they did, God bless them. These books have been a revelation to me. I have often gone ahead hoping for the best that what I was doing was the right thing. After reading 'On children and death' and especially 'Aids : the ultimate challenge' many things fell into place.

When I arrive at the Hospital I change ,but not into a white gown. I change into a clown suit. You see I was deeply moved by "Patch Adams", the movie starring Robin Williams. I think that movie has a lot to teach not only doctors about their attitude towards patients but all of the helping professions, including chaplains.

So I dress up like a big toy and I go to spend a morning with the little ones(from 2 months to 5 years). That includes playing with them, helping a teacher in the teaching process, or just picking up one who is very sad today and giving him lots of hugs to make him or her feel very special. Then we might take the kids out to the play ground if the weather is fine and if not we stay inside, painting their faces like butterflies or cats or little clowns.

While the small children lunch I spend some time talking to the staff of the department – all women – have a meal with them, see what's the biggest need in the ward and then get sponsors' money to buy things needed for the developing or nurturing of the children.

Then - it's nap time. Singing a song has become something of a "ritual" and now they will not let me go without singing.

While they are asleep I pray for them and then go to another department for teenagers with their mothers. My work involves going from room to room talking to the mothers, listening to the complaints, lingering perhaps in someone's room for an hour if a child is bedridden, and talking to him or her if there are any fears or requests.

Often I spend time in the playroom, among the table football and the computer games. But sometimes, if there is a child on the ward who has lapsed into a coma, the playroom will be empty, and I find myself walking from room to room, listening as a mother expresses her fears that her son or daughter is going to be next.

If it is Wednesday or Friday there will be a "Questions and Answers" meeting where children are encouraged to ask any kind of question and we (a head nurse, psychologist and chaplain) promise to give them an answer right away or in 3 days time. If not we bring a cake.

The purpose of these meetings is that as a chaplain I would encourage them to ask "difficult" questions about their life now, and on what's waiting for them in the future. Thus the spell of isolation and 'only-my-own-problem' will be broken, and children will be able to share their stories and fears and hopes and ways of overcoming. We are in fact trying to facilitate a self help group for these kids. It has worked out well. Questions come about almost everything, from "how heavy is a molecule" to "how long could my treatment last". And what is great is that they don't stop asking questions after the meeting ends. Now almost every day with them begins with one question or another.

You see when they actually get to used to asking you questions (which is unusual in Russia; patients generally know little if anything of their progress or regress, and doctor - patient communication is almost nonexistent) it is more likely that they will be willing to answer your questions. It's just about building mutual trusting relationships, I think.

Our motto has always been "Do to them something extra that no one else does". They had medical care,

but had no play room, we made them a play room; they had no one to care for them, to hug them and talk to them, we gave them a teacher (or 'tutor' might be a better word. I do not like the word teacher. You see, in Russian there is a word VOSPITATEL which means "the one, who brings up, nourishes, nurtures"); there was no one to show them the world, so we started taking them out from the Hospital (first time in 5 years!) and taking them to various places of our beautiful city. Now they have it all, but there was no one to sing a song when they go to bed, so we did it. What's next? We are ready to answer...

Difficult things

The most difficult is not actually dealing with the dying child or siblings, I found. To me, it is heart breaking to go home at the end of the day and see my son, just over a year and a half old now, running to me with a smile and his arms spread. Heartbreaking because, just 2 hours previously I have left 29 just like him to wander around the Hospital ward, knowing that there is a better life and not being able to have it.

But naturally the death of a child is always a difficult experience especially when you two made friends and spent some time together.

Feeling like "May day!" or "Retreat!"

Every so often I feel very bad. Usually after another death of a child that I got to know. At times like this I wish I could do something to stop it all together. There is a certain sense of helplessness.

It is always helpful to talk to someone, to let the steam out. My wife worked at the same hospital before the birth of our son. She understands. My leaders at The Salvation Army are experienced and caring people and their door is always open when I need them. I pray and this sustains me daily. Sometimes to go out where no one can see me and just cry out loud helps too.

Blessings

When a few minutes before her death a 14 year old grabs your hand as you come close to the bed and says "here comes my friend, sit down with me" I know for sure that he is going to Heaven, no doubt about it. He knows who I am and what I believe in

and in accepting my beliefs he kind of says "I agree with you, God is not going to leave me". That's where I find blessing.

I wish...

I wish to be unemployed. I wish that children would stop getting AIDS. I wish that children would not die or that they will finally find a vaccine.

I wish I could adopt all of the children, all 29, or at least build a house for them where they would feel loved and cared for, where they could grow and be independent, and if they die, then die with dignity and in peace. A kind of family children's home. I have many drawings of it in my mind.

I wish I could take the children out from the hospital for a day trip in a van more often than we do now, so that they can see the "bigger" world.

I wish that society would change it's ignorant "wall" attitude and accept children with AIDS. And I am ready to do all that there is to facilitate this change by word or deed.

I have lots of pictures from the time when we started up to the present. But they only can be shown by me and cannot be published. Older children never give permission for their photographs to be published. They are afraid that if this becomes known in their neighborhood, they and their family would be in trouble, and their fears are well founded. I also have a 30 min film that was made for a big TV campaign in Norway. But it can only be viewed in my presence. I hope that one day things will be different.

Good news!

Let me end by telling you something good. I have just got hold of an address of Compassionate Friends in Russia! They have just started in Moscow and I really hope that we can work in close cooperation.

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