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O ČOM SA NEHOVORÍ – A MALO BY SA

The world in front of the window and the world behind the window - these two worlds are completely different.

Outside, it has been drizzling since early hours in the morning. Nobody likes it because it makes you feel depressed. Heavy fog is hanging over the town. People at the bus stop are packed under a small roof. Everybody is in a hurry. The woman on the other side of the road is shouting angrily at a taxi driver who has just splashed some muddy water on her light brown coat. A group of three or four teenagers dressed in bright coloured jackets are crossing the road laughing out loudly. They are as light-hearted as the sparrows twittering on the roof of a nearby block of flats.

Inside, there is a young girl sitting at the window watching those sparrows. And she is jealous of their freedom. She wishes to be able to fly far away as they can do. She is seventeen years old and she is bald. Bald but still pretty. Yesterday, it was her eighteenth chemo treatment. Yes, you are right - she is staying at children's oncology. And she feels so different from those happy teenagers walking in the street. A year ago she was the same as they are but the last twelve months have changed her a lot. She has a different point of view because she has experienced so much. However, she feels misunderstood by her friends of the same age.

Why is it like this? In fact, the word *cancer* is really a taboo in our society and very few young people know about this subject. Why don't we want to talk about it? Are we afraid of it? Maybe we are terrified too much to find some suitable phrases. Nevertheless, people fighting this hard disease need our help - at least our physical support. But how can we lend them a hand if we ourselves need a help? Would you like to know how they feel? Let me tell you my story.

This seventeen-year-old girl is me. Last February I started my treatment at children's oncology in Bratislava because of bone cancer in my left knee. After my first chemo I lost all of my hair. It was a really dramatic change for me as I had never cut my hair since my birth and it had come down to my waist. And suddenly flocks of my hair were falling out and after few days I found myself bald.

I didn’t cry but the first glance in the mirror was painful. I started to wear a wig but I felt hot in it. Drops of sweat were rolling down my face. I felt pretty but very uncomfortable. And still in front of the mirror in our bathroom I felt like a thin alien. I needed to look naturally pretty again. This psychical state lasted for several months until I found an American website joining children suffering from hair loss who were fighting for the fabrication of a bald Barbie doll as a symbol of beauty independent of hair. It was called Beautiful and bald Barbie and there I found many photographs of young bald girls. And I realised how beautiful they were. It was another kind of beauty – beauty coming from their inside. And they were beautiful INDEED. I didn’t feel like an alien anymore. I understood I was a flower bud waiting for its time to bloom.

My typical day in hospital started at six o’clock in the morning by a routine blood taking. After being given chemotherapy numbers of my blood cells always went down. Many times I had such few leukocytes that my immune system wasn’t able to protect my organism against any bacterial or viral infection. That’s why my blood results were a deciding factor – if they were too low I had to stay alone in an isolated room and nobody could be with me except for my mum who had to wear special clothes and surgical mask like in an operating room. Neither could I leave my room nor even open the window. It was hundred times worse than being at solitary confinement in prison. This state lasted for at least one or two weeks, sometimes even more and it was accompanied with fever, inflammations, antibiotics, vomiting and cruel aphthae (mouth ulcers). Nothing helped just waiting patiently until my bone marrow regenerated and started producing new blood cells.

These times, being shut in the isolation, were very hard. I would say they were one of the worst days during my treatment. And it was not just because of my terrible health condition. Moreover, it was caused by being ALONE. I wasn't allowed to be with anybody. I couldn't telephone because I wasn't able to speak as my mouth was completely destroyed and extremely painful. My only connection with the outside world was the Internet.

However, this type of communication wasn't ideal at all. My friends usually couldn't imagine my life, my problems or my feelings. Some of them were afraid to ask me how I was doing. Or they didn't know what to write or how to start a conversation. I don't blame them for it because I think I would have been the same at their place.

What's more, we didn't have many subjects to discuss in common. They couldn't imagine my situation and I couldn't talk about school because it was something light years away from me. I needed to talk about my feelings but there were very few people capable of listening to it. And if they were they usually give me a lot of well-meaning advice which just irritated me. Nowadays, I laugh at it but at that time it made me really sad. I only wanted them to listen and try to feel with me.

During my first week in hospital I got a countless number of phone calls and text messages. But as time went by they became more rare and rare. The first interest slowly kept on fading away. Finally I realised that I was using only about five telephone numbers. On the other hand, some people, who I wasn't so close to, became my very best friends. It was because I feel from them a real interest, love and the fact that they cared a lot about my being alive. I shared my joy and worry with those who stayed with me till the end. It is reasonable when we say: A friend in need is a friend indeed.

Besides, the days out of hospital look normal but they are not. Every check-up is full of stress and expectations: will it be OK or will I have to come back to hospital? Will I be able to go to school or will the next treatment destroy my attempt to live normally? Will it rob me again of everything other people take for granted? These unpronounced questions keep on torturing me. Sometimes when other people are laughing I cannot. Why? I still think of my friends who have just relapsed, their fear, unanswered phone, off-lined Facebook… the fight of life and death. I know we are scared even at the slightest presence of pain anywhere in the body. What guarantee do I have? The guarantee of God´s keeping power.

Last but not least I would like to mention a doctor who I met during my treatment. His interest and kindness were remarkable. We thanked him for his help and then he said: "I hadn´t been like that before. But several years ago I had to undergo eight difficult operations and chemotherapy as well. It changed my life and behaviour. I know what it is all about." That´s why I would like to remark the importance of the behaviour of a hospital staff. I, as a long-time patient having to cope with difficult circumstances and psychical states, was in need of understanding, love and patience from doctors as well as nurses. But in the hectic world we live in there is too little time to show and talk about our emotions. Everybody is in a hurry with no exception of the doctors. I was lacking in possibilities to feel free to speak to them, to ask everything I was worried about, to discuss my problems and treatment… Yes, time and willingness were often missing.

Flashing back all my memories and remembering everybody I got to know last year I still believe I have learned how to thank God for every new morning, how to believe when everything goes wrong and I have understood the dimension of internal beauty. My dream is to break the taboo of *cancer* among young people. For this reason I had some photos of me without hair done in memory of “bald beauty”. ☺ And I wish my experience would help someone in a similar situation.

In conclusion, young people with cancer need the support of all of you because they miss the feeling of being normal like everybody else. Many teenagers are interested only in what to wear, where to go or how to entertain themselves and they have no idea of the circumstances that the young cancer fighters face. If we don’t speak about their feelings as well as everything connected with the treatment, nothing will change. Do not create a communication barrier because words are the keys to open a prison of thoughts. And what message would I like to leave? **Help us feel equal to you!**