

EU Health Prize for Journalists 2011

Living with loss

By Georgiana Ilie, National nominee for Romania

Sometimes, death comes as the natural end to a fulfilled life. At other times though, it comes as an unexpected drama, a fact that is unjust and painful not only for the person who passes away, but also, and even more so, for those left behind. Where do you find support and comfort when you lose someone to a terminal disease or an accident? Who lends you a helping hand? What happens if nobody does?

In the following four articles, I have tried to explore the various aspects of our relationship with death and disease, with the way it affects our lives and our ability to be happy. The series addresses questions we ask ourselves when we experience the loss of someone dear. As a whole, the project tries to build a bridge for communication between those who find this painful experience only too familiar.

The way back to a normal life

My mother died in June 2006. She was almost 46, and only 15 months had gone by since she had been diagnosed with stage II cervical cancer. She went through radiotherapy, hysterectomy and chemotherapy - but the cancer spread to her lymph nodes, and then nothing could save her. Her family – my grandmother, 87 years old at the time, my brother and me – we were left behind. We were to reinvent our lives without our ultimate reference point: Mother. It was horribly hard.

On one of my shelves there is a jar with coloured salt crystals, the kind that you can buy in interior design shops. Different layers of salt - violet, blue, yellow, pink, brown and green - seem to create some aesthetic design. But that is not their purpose.

Each colour is a memory of mum. Violet is for the time she was sick in a hospital bed, and the doctors told us she might die in three months. Blue is for a day, six months before that, when she came over to my place for the last time and we played like teenagers, putting on make-up and taking pictures. Brown is for the days, one month before she

died, when she could no longer get out of bed, but we were pretending everything would be fine. Green is for year 2000, when I found out from a friend visiting from Hungary that my mother spoke fluent English. I'd had no idea. A blend of happy and sad memories. Things I had refused to think about after her death, because the instant her face came to mind, all I could see was the incredible suffering she had gone through during her last year.

I could only remember her lying in bed, putting on a nonchalant smile, while the pain showed clearly on her face. And so I decided to stop thinking about her at all. I hid the pictures, I avoided going into her room, I gave or threw away many of her things. My grandmother and my mother's friends drove me crazy when they talked about funny or moving stories with her as the main character. Or when they chatted about the things you're supposed to do during the first year: the alms, the donations, church and cemetery rituals. I didn't need these rituals, and I couldn't see why she would. She had died and that was it. Please, let's not talk about this anymore.

Two years after her death, I started feeling very sick. It always happened when I was alone, most of the times when I was alone on the street. I would start thinking that my grandmother would die. Or that a friend was ill. Or that another friend was all alone in a foreign country. I would get a lump in my throat, and I would start to cry uncontrollably. Looking at myself from the outside, I realised it wasn't normal to cry on the street for things that had not happened yet. I thought to myself: I must be losing my mind. This must be the reason. What person in her right mind would behave like that? If I go crazy, will they put me in a mental hospital? How long for? Will they put me in a straight jacket? That made me cry harder. Who would take care of my brother and my grandmother? I kept on walking and crying. Once I arrived at my destination, all my fear would suddenly disappear. I would wipe my tears away and I would start normal conversations. But deep inside, I knew the isolation room was just around the corner.

Christmas 2008 was the worst. I couldn't sleep, I cried all the time I was left alone, and I couldn't get rid of the lump in my throat anymore. I was overwhelmed with despair, but if someone asked me where the crying and despair came from, I wouldn't have been able to answer. It seemed my whole being had switched to a new state of matter, that of tears.

The feeling that I would die of pain unless I do something about this, gave me the strength to admit, one night, that I needed help if I ever wanted to lead a normal life again.

I found my support in a psychotherapist recommended by a friend. That's how my road back to normality started to unwind. Under her guidance, I mourned my mother's death. I brought her image back in my mind and I used chalk to colour the salt crystals I put in this jar. Now I can look at it without crying. Above all, I found out that what I was going through was by no means an exception. I wasn't losing my mind, I was just suffering from the anxiety caused by the death of my mother and by the circumstances around it. I realised that when the doctors gave the terminal diagnosis only to me, and not to my mother, and I didn't know how to tell her and to prepare her for what came next, I developed a guilt that consumed me from within - until I could no longer take it. And I found out I can feel whole again. I opened my mind to all the exercises my therapist proposed, I did my homework, I was a model student. Soon I started to see improvements. The panic attacks came more seldom, and when they did, I could control them through respiration and logical reasoning. Then they disappeared altogether. I managed to heal a wound and get over the loneliness and helplessness I felt ever since my mother became ill.

What was left was a frustrating feeling: much of this pain could have been avoided. I felt that if the doctors had had a bit more respect for us, if they had communicated the diagnosis both to me and my mother – as they are required by law, in fact – we could have enjoyed some peaceful months together. That if we, as a family, had had help from professionals, or at least the chance to talk to other families going through similar circumstances, we would have found it easier to accept her loss. That if I had seen the healing role of our death-related traditions, I would have gotten some comfort, as my grandmother seemed to have.

At first, I was ashamed to tell anyone I was having psychotherapy. But then, seeing how my life was changing, how I found my motivation and peace again, all I wanted to do was to share my experience with other people - maybe, just maybe, to give them the power to ask for help in similar situations.

We all have a duty to be happy: for us and for the ones who loved us and went away.

"The Brave Ones" learn to survive

In Romania, there are very few support networks for patients with cancer and their families. This in spite of the fact that each year, 45 000 Romanians die as a result of tumours and another 60 000 are diagnosed with cancer. It doesn't have to be a formal network. For some, the opportunity simply to meet other families going through the same circumstances helps the most.

Paul Șilian first joined the "Little People" Association (www.thelittle-people.org) in 2007. He was 16 and already recovered from two brain operations – in Cluj and Budapest – to remove a tumour. "I had put my studies on hold for two years, so when I went back I felt like a stranger", he recalls. "I thought I would find someone to talk to there." His doctors told him about this Association, established by Katie and Shajjad Rizvi in Cluj in 1996. So Paul and his mother gave it a try.

He found friends among "The Brave Ones" – a community of adolescent cancer survivors created by the Association. "We have weekly activities, sometimes meetings, but what I enjoy most is when we go out for a film or a coffee, when we play cards or simply chat", says Paul. He got back into his normal life-rhythm again, despite going through seemingly hopeless situations. He was diagnosed with cancer when he was 14, just weeks after his father had died. The fight lasted two years.

"It's tougher for teenagers", says Shajjad Rizvi. "Children adapt faster, but teenagers are already going through a difficult period in their life. The time they have to spend in a hospital has terrible effects, changes the way they look and makes them lose friends and years of studies..." Before working in Romania, Shajjad, London-born, and Katie, Budapest-born, had been giving a hand in paediatric hospitals in Bosnia for three years. Starting 1996, they came to Cluj to establish one of the first organisations for the emotional recovery of children and teenagers diagnosed with cancer. A process that has to involve the families, too, because they're just as much affected, says Rizvi. "When they leave the hospital, they all fear they would have to come back, because the recurrence rate is higher for younger children. And they live with this overwhelming stress."

In the beginning, Little People was in hospitals only, interacting with children in the oncology department. Through volunteers and therapists (the only employees as such), they managed to help families and children adapt to the illness and the treatment and to make them feel someone understands them. "With time", Rizvi says, "we realized they also need help after they're discharged, and that there's absolutely no one they can go to for that." That's how "The Brave Ones" saw the light of day. They were the survivors. The support network widened to three major hospitals: the "Prof. Dr Ion Chiricuță" Institute of Oncology in Cluj-Napoca, the Department of Oncology of the Clinical Paediatric Hospital 2 in Cluj-Napoca, and the "Prof. Dr Al. Trestioreanu" Institute of Oncology in Bucharest. Rizvi doesn't think it's enough though. "Support should be available all over the country."

The projects are based on volunteering - during last year alone, volunteer workers put in a total of 100 000 hours for Little People. The people who give up their time for such projects come from all backgrounds – from businesspeople to psychology or medicine students. But the most enthusiastic are the members of our community, "The Brave Ones". "We wouldn't have dreamed about asking them to become volunteers", says Rizvi, "since the impact of the period spent in the hospital differs from one patient to the other. You never know what memories or reactions going back there could trigger. But they offered to do it." Not all of them, but those who did set off a significant change in the attitude of both children and families. "They are the best among the volunteers, because nobody understands the situation better."

Paul Șilian is one of those who offered to work with the children in the hospitals. Every week he spends at least a few hours with them and, simply by being alive and showing that he has a normal life, he gives hope to their families. And he never goes there alone: some of his peers from school (the very ones amongst whom he felt like a stranger when he returned) have joined him as volunteers – the best proof of the power of a role model to return the good he received, and add to it.

The news that no one wants to give

Who has to give the sad news to the families of accident victims? How should they do it? How are they trained to give it in such a way as not to aggravate the trauma?

The answer is very short: nobody has to do it. Under Romanian law, no specific institution is responsible for informing the victim's family.

The Ministry of Administration and Internal Affairs thinks that responsibility belongs to the Department for Registration of Population and Database Management, to the Directorate General for Passports or to the forensic experts.

The Department for Registration of Population and Database Management says their only duty is to help investigators to identify persons.

The Directorate General for Passports says it has no such duties.

The "Mina Minovici" National Institute of Forensic Medicine does not handle this because it does not conduct investigations.

Dana Tițian, spokesperson for the body that *does* conduct investigations (the Public Ministry) says that informing the family cannot be the task of the prosecutors, since they arrive at the incident scene only after the preliminary police investigation is concluded.

The Inspectorate-General for Emergency Situations deals with all fires, natural disasters and rescue operations and offers urgent medical help through the SMURD rescue service. But all it is mandated to do is to draft an expert report and send it to the police.

And finally, according to law 218/2002 on the organisation and functioning of the Romanian police, the police have no responsibility in this field. Chief commissioner Christian Ciocan, a spokesman for the Bucharest police confirms this. "Policemen have no obligation to inform the family, but most of the time they are the ones who do it, simply because they interact with the family during the investigation. Even more so in small towns or villages, where people know each other." The way they give the news depends entirely on their personality, since there is no methodology and no courses for that at the Police Academy. A few years ago, there was an initiative establishing that the spokesperson in each county should be the one informing the family, together with a psychologist. But the idea was abandoned. Ciocan doesn't know why, because he found it efficient. "It would have been a good idea: you give this responsibility to the police, but

you at least teach them how to do it. Telling a person that his or her child has died is a very delicate and difficult matter. It's not easy for the policeman, either."

In 2010, over 2 300 people have died in road accidents alone. In 2009, there had been 2 729 deaths according to the Romanian police reports. Every year, around 13 000 people die in violent circumstances (injuries, poisoning, other external causes) that can require an investigation and, therefore, involve the police. The police showed how unprepared they were after the fire that broke out at the Giulești Maternity, when they called a family to tell them that their baby had died in the fire. In fact, the baby had survived and was in the intensive care unit of the "Grigore Alexandrescu" hospital. When the family came at the hospital, they found out it had been a mistake. The baby was alive. But it died the second day. The tragedy of this family – their baby was born prematurely, then burnt alive in the hospital, then saved only to die later because of the wounds – was ten times amplified by the unintentional cruelty of a bureaucratic error and the tactlessness of a policeman who could think of no better way of giving the news than by phone.

The way such announcements are made, particularly when they are definitive and traumatic, like in the case of a violent or unexpected death, has a huge impact on the receiver's ability to accept reality and overcome pain. Psychiatrist and Psychotherapist Dr Mugur Ciumăgeanu says it is not always necessary to use a protocol. What matters the most is the attitude, which has to transfer the so-called "E" factor. That is, *expectancy*, the idea that life goes on.

If they are unprepared and ungifted for communication, the bearers of bad news risk falling into the two extremes: either they are too dry, and cannot offer any comfort, or worse, they fall into the trap of being too compassionate, and thus involuntarily send a more negative message – that the situation is hopeless. In the longer term, such attitudes disable natural crisis management mechanisms. In other words, being cold doesn't help, but being too soft, treating the people receiving the news as victims and crying along with them is much worse. The best solution is to communicate the facts while sending the message that the crisis is something which, with time, they will overcome. Thus, the family is being offered a healthy attitude, instead of an emotion that can degenerate.

People who get bad news in aggravating circumstances lose much of their ability to recover and can develop symptoms of post-traumatic stress (PTSD). *A cognitive model of post-traumatic stress disorder*, by Anke Ehlers and David M. Clark, defines PTSD as the victim's incapacity to recover emotionally after a traumatic event. The patients refuse to think about the specific event, become emotionally detached or involuntarily relive the situation, over and over again. Quite often, they start blaming themselves for what happened or find some reason to explain why they became victims. They begin to see life in a negative way and they are overwhelmed by previously non-existent fears. They feel alone and misunderstood and they become withdrawn. Symptoms can vary according to the situation or the sensitivity of each person, but they always affect the quality of life on a long term.

And all this can be prevented if those who have to give the news nobody wants to give are trained to do it in such a way as to provoke as little pain as possible.

Healing through rituals

Over the centuries, folk wisdom created coherent rituals to help souls cross to the other side and, at the same time, to offer comfort to the family. With more and more communities being urbanised and changing their profile, these rituals are dying out. What's left to replace them?

In the old cemetery in Bocsig, in the county of Arad, you can immediately find out who died young or old. Dr Georgeta Roşu, Museology Director at the Village Museum in Bucharest, explains that the crosses of people who died old are short, less than a metre high, whereas young people who died before getting married have a most stately cross, sculpted out of the tallest tree in the forest. This is how the villagers show their regret for the sudden death.

The concept of death – and the word itself – does not exist in these rituals. The event is seen as a passage from this world to the next. However, the wisdom of old has a different approach to natural death, that followed a full life, than to an untimely death, that snatched away the life of a person who didn't get to accomplish his/her role in the family and the community. Thus, one acknowledges not only the loss of a person, but also the loss of his/her potential. At the same time, one brings comfort to the affected family.

Romanian burial rituals have pre-Christian origins. They have been assimilated and accepted by Christian-Orthodox dogma, says Dr Roşu, because they contain generally accepted answers to the great mystery of the final passage. The Romanian peasant believes in isomorphism – the reflection of our life on Earth, on to the other side. After death the soul cannot help itself, so we must help it to find its place and prevent it from wandering between two worlds. "That is why people are buried close to the graves of relatives, who can welcome the soul and guide it to the other side." For this same reason, the ones left behind follow a series a rituals for a seven-year period: giving alms, offering incense, giving away objects that belonged to the departed. A heritage going back hundreds, even thousands of years, these rituals are meant to stop the dead from getting upset and coming back to haunt the family. "These days, nobody can tell you why we do this", says Dr Roşu, "only that 'this is what we're supposed to do.' But in fact, following these traditions brings comfort."

Traditions differ from region to region, sometimes even from village to village. In the county of Gorj, people paint icons on crosses and plant a tree in front of the house. Or they fill pumpkins with food and a burning candle, and float them on water. In the regions of Argeş and Moldova, they cut down a small tree and decorate it with protective symbols (suns, angels, ladders, hands) made from dough. In Vrancea, they build a symbolic house containing all the necessary items, such as a bed with linen, cooking pots and tools, and give it to someone in need. All these are meant to guide and soften the departed soul. Some things are the same throughout the whole country: neighbours and friends are involved in the process and take care of the practical aspects of these traditions, so that the family can keep vigil and say farewell in peace.

For 40 days (or 6 weeks) after the funeral, it is said that the soul roams about the places where he/she used to live. During this time, people place a glass of water in each house, so that the departed doesn't go thirsty. The 40-day period is important in other parts of the world too. Ioana Fruntelatã, associate professor of ethnology and folklore at the University of Bucharest's Faculty of Letters says this same symbolic number appears in The Tibetan Book of the Dead and in The Egyptian Book of the Dead. Present in Romanian pre-Christian traditions, the period bears particular significance for Christians and Muslims, as well. According to one Islamic tradition, the extended family comes to

live for 40 days with those who have lost someone dear, to help them overcome the difficult times. At the end of the 40 days, the soul goes to be judged and it needs help to pass to the other side for good. Such help comes in the shape of "prayers and philanthropic deeds", says Gheorghe Istodor, a priest and a professor at the University of Bucharest's Faculty of Theology. The so-called "parastas" (coming from the Greek word "parástasis", which means "beyond death") is a religious mass and funeral feast meant to do just that.

Such traditions survive, says Ioana Fruntelată, because they are the only customs to offer answers to the void of death. Nobody knows what happens after you die, so the ritual gives an acceptable answer, whether you are religious or not. "People need meaning, and the traditions will continue to exist, side by side with religious practices, because there are no other answers", she continues. Her words refer only to rural areas and small communities. In big cities, where communities are disconnected and people share no common history or understanding of rituals, traditions lose their power. "Certainly, the therapeutic role diminishes if people don't understand their purpose. One of the main traits of rituals is the lack of haste. The funeral procession itself takes place on foot, passing through all the places that were dear to the departed. In cities, what prevails is the wish to get rid of the process as easy and as fast as possible."

Professor Istodor says that, in the eyes of the Orthodox Church, man's relationship with divinity is based on an archaic certainty that the soul is immortal. The rite (a "parastas" and a mass at regular intervals after burial – 3 and 9 days, 3 and 6 weeks, 3, 6 and 12 months) developed in a natural way, to fight against the real death – oblivion. These are occasions to remember the dear ones, to keep them alive in the memory of the family, but also to show the family that they have the community's support. "The first year is a critical period," he says, "and the role of these rituals is to keep the family close to the church. Those who turn their backs to them are giving up a form of help. Pain is more difficult to bear when you are alone."

Ioana Fruntelată adds that, no matter the religion or belief, the disappearance of the rituals leaves a hole in the feeling of safety, a void that replaces what was once certainty. "It is difficult to replace a model which took centuries to form." And since, at least for

now, we have no other answers to questions about death, the void seems to extend more and more.