

# Interview with Muriel Scibilia

Head of Communications at UNCTAD  
and the author of  
**Côté nuit,  
côté soleil...**

Muriel Scibilia is a former journalist, Head of Communication at the United Nations Conference on Trade and Development (UNCTAD). Despite a busy and hectic professional life, she has spent more than a year dedicating her free time to writing a book entitled *Côté nuit, côté soleil ...* which discusses the very sensitive subject of adolescent cancer. Nobody talks much about how young people and children handle such a difficult illness and Ms Scibilia's book is a very poignant account that leaves nobody indifferent. Her main objective is to give us all some ideas on what to do and what not to do, ideas about how you should talk to young people going through this terrible experience. Here is Muriel Scibilia...

**Q: You have just written a book of evidence on youth and cancer. Could you tell us something about it?**

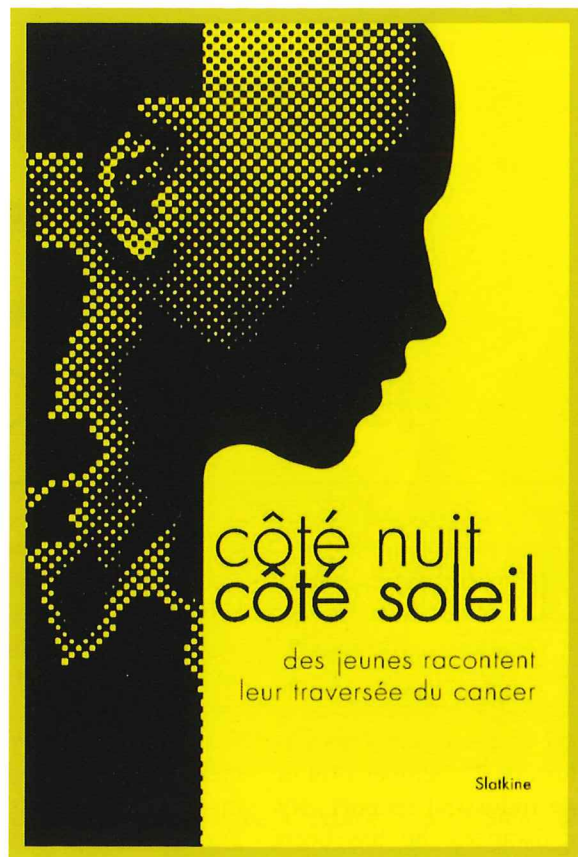
Actually, what I did was write a journalistic book entitled "*Côté nuit, côté soleil ...*" The concept was based on the idea of letting ten adolescents tell their own stories. All of them had had cancer and had survived. It is the story of these young adolescents.

I asked them: "What was the most horrible thing that you had to go through?" They had to make an effort to try to relive what they had experienced and to remind themselves what the most terrible aspects were. Sometimes the answers are quite surprising. For instance, for a young girl the most terrible thing was losing her hair. This is something that you would not or could not imagine when you're an outsider. You would think perhaps that the operations, the chemotherapy must be the most awful thing to endure, but no -- in this case it was the loss of her hair.

The other question was: "What was the most amazing thing, the most magical thing you experienced?" As an outsider thinking about cancer and teenagers, everyone is afraid or feels awkward about it,

insecure. Most people do not want to be confronted with this issue. So they escape, simply because it's scary, because it affects children and you do not want to see them suffer. This is a legitimate reaction. However, not everything is completely negative, because nice things do happen, also incredible things, beautiful things. These can be moments or gestures of solidarity, quite unexpected gifts, travel experiences. This is why I asked them to tell me the most exceptional thing that had happened to them. The third question I asked was: "How did the fact that you have been seriously ill affect you and your vision of life?"

What interested me in particular was to understand how ten years later this experience had affected their lives. I wanted to know if they had a goal, or something that made them move ahead. I asked them: "You have been so close to death what has this done to you? Does life have a different sense? Does it paralyze you?" The answers I received are very different from one person to another. For some, this experience had ruined their future. For instance, there was the young girl



who dreamed of becoming a chef. She had cancer and things did not turn out well for her because she is now handicapped. She can walk but she cannot stand up for long. The result is that she cannot become a chef because this is a profession that requires a lot of standing. So this cancer destroyed her dreams and ruined her future. For others it is the opposite. Having going through a difficult experience gives them a rage and a desire to live. One of them told me: "I know that I'll lose friends. I know that a lot of negative things will happen to me in life. It will make me sad, but it will never destroy me."

**Q: As Head of Communication at UNCTAD, why have you embarked on such a venture?**

I wanted the public to understand what you should do and what you should not do. I've realized that you feel very awkward; you feel helpless. Both you and the people in your environment. You would like to do something, but you feel lost. If you read and listen to what these adolescents say, you can understand what you can do easily without having to be told to do it. These are often small things that can make a huge difference to the person. One, for instance, told me: "I do not want anyone talking about my illness. What did me the most good was when someone came and played video games with me. That was what I needed there and then." When someone in your entourage is suffering from these problems and you are going to pay them a visit in hospital, after reading this you know a little bit more about what to do. You can play games with them, or simply read a book and, in this way, you do the young person good. This is not a huge investment that costs a lot of money; it is a way to behave -- just being there.

That is one of the aspects. Another thing is community support, in both its most narrow and broadest sense. This means that the way people react with teenagers is different.

Teenagers learning about life are fragile, and you can easily damage them. There are things that work and things that do not work. When the environment -- the school, the community (not just the family) -- is involved, it's also very positive in giving them the energy to fight and move forward.

Then, it is also the story of my daughter who suffered from cancer. While at the hospital with her I met other young people whom I cared about and I wondered how life had evolved for them. I found it interesting and useful to share their experiences with a larger number of people. What they say is valuable and it should be heard; very often we do not give them the opportunity to express themselves by talking to them. There may be lots of studies, but they do not let the teenagers talk.

**Q: Do you think we do not talk enough about cancer?**

The situation has changed. Today there is quite a lot of talk about cancer. A few years ago in France nobody liked to say the word "cancer". What people said was that a person had died "after a long illness",

and the name of the illness was not mentioned. This issue about cancer is no longer taboo. There are magazine articles, TV programmes, etc. However, children and adolescent cancer is still something we talk about very little, perhaps for legitimate reasons because it is very scary. This is a total injustice. Today, eight out of ten children recover. This is a huge figure compared to a few years back. However, the question we must and should ask is: "Has the person indeed been cured?" They have survived but what about the consequences -- the long-term consequences -- for these young people? They can end up disabled, suffer from cardio-vascular problems, become sterile, and endure other problems in their adult life. There are indeed a lot of things to look into. ■

*If you want to learn more about how to behave with or talk to persons with cancer, read Muriel Scibilia's book. She has generously granted all the rights of the book to an association conducting cancer research for children and adolescents.*

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