A Mile in
My Shoes
HEALTH & SOCIAL CARE

# MYRA BLUEBOND-LANGNER

## SIZE 6

I need to take you back to a Sunday in September, in Chicago, forty five years ago. When a man in a long, white coat handed me a stopwatch. Told me to go and stand at the end of the bed and tell him when twenty minutes had passed. I did, and he said “OK, that's it, I call it. Time.” I looked at the stopwatch – “Seven twenty seven,” I replied. The child had died. A child that I had come to know, as the leader of the bathroom seminars held just outside the oncology clinic. The child who drew pictures of herself on blood red crosses, who spoke of the medicines running out. Who knew that the chemotherapy was affecting her liver and who told her mother to take her sister camping that weekend. The weekend when she would die.

So I'm Myra Bluebond-Langner. I'm the professor and True Colors Chair in palliative care for children and young people at UCL Institute of Child Health - the Louis Dundas centre for children's palliative care. I was hired to be a professor, do research, contribute to the evidence base in children's palliative care. The other part of my job is to better integrate the research aspects of palliative care with the clinical aspects. So the Louis Dundas Center has a clinical team as well as an academic unit, and it's my job to bring them together. So, for me, when I think about what needs to be done, I measure it against, will the research we do inform practice and policy, so the children's suffering is reduced. What can we learn from the clinician about where the gaps are in research, so that we can bring this about.

Studying children with cancer was not what I had originally planned. I had planned to do what most anthropologists are trained to do - that is to live in another culture. So, how did I find myself at the end of the bed, and how did this have to do anything with my journey? So, to explain this I need to take you to 1968 - I want to recall that time, because when I first went to Third Mesa on the Hopi reservation in Arizona, my plan was to study identity, and then, although the project studying Native American cultures was approved, I decided not to go. The reasons were matters of tribal and government politics. People wanted access to my field notes and I said no, because I didn't know how they would be used or to what end. So what did I do? Here I was, a doctoral student, what am I gonna do for my dissertation? Well, that spring, I was writing a paper on how children use phrases like ‘I don’t feel good, my head hurts,’ and my professor said “Myra, why don’t you go and see how children who are really sick talk?” And at the hospital I was immediately struck by children who knew about their illness. I was also struck by the fact that the adults thought they knew very little, and I began to realise that the question I was interested in, was how do children learn information that's kept secret from them and how do they communicate that awareness. It was through that that I decided that if I wanted to understand children's identity, how children form an identity, I needed to study these children. And I was interested, then, in how children came to know themselves in situations where that identity was tolerated. Situations in which it was celebrated and situations where it was not to be discussed at all. Despite the obvious differences between studying Native American cultures and doing research in paediatric palliative care, there's actually complete continuity, the tools, approaches, perspectives that I used then, are still bearing fruit now.

To my core I'm an anthropologist. I'm interested in understanding people's engagement with the world and with others, that different people do different things in different ways and all people have to confront certain issues in life and different peoples may do it differently. My work in this area is more than forty five years and I think our understanding of children with life limiting illnesses has changed since the time I've been involved. When I began, everyone thought the children didn't know, couldn't know, and perhaps shouldn't know, they were dying, but my experience was telling me something else. By living with these children for days, nights, weekends, in the hospital and at home, I found these children were not only aware of their illness, but that their awareness changed over time. Perhaps the reason why people had missed it before was they weren't aware that the children were engaging in mutual pretence. That's where everyone knows but no one will say, and that was true for the parents and for the children. It's the elephant in the room.

There was a boy, Jeffrey, who captured for me what children know and why they'll engage in mutual pretence and not tell. Jeffrey was a boy who would always yell at this mother, he was constantly yelling at her - now you have to remember I'm an anthropologist not a psychologist, So I'm sure I didn't ask this in the best possible way! I said “Jeffrey, why do you always yell at your mother?” and he said to me “Then she won't miss me when I'm gone.” Later I asked Jeffrey’s mother “Why do you think Jeffrey yells at you so much?” and she said “Myra, he knows when I can't take it in that room any more. And he knows if he yells at me, I'll leave. He also knows I'll come back.”

I think we hear in that most poignant of conversations, by mother and child, each's relationship and desire to protect the other, and I think that's why we've so often missed what these children understand. Children the world over are capable of interpreting the behaviour of others and forging a line of action based on those interpretations, but particular interpretations may vary. I feel what's at stake with our work is our very humanity. Am I optimistic about the field and going forward? Will we see better palliative care for children? Will we see greater understanding of children? Yes, yes, and yes. But the goals and the ideas of palliative care should not be unique to palliative care, rather woven into the whole process of care and treatment. We should always be treating the whole person and listening, not only to the clinicians, not just listening to the parents, not just listening to the children, but listening to everyone. Each child's death diminishes us in some way, but each child's death also contributes to us. It's a wake up call to appreciate what we have and I think we constantly need to be aware of that. I certainly am.