

## A sense of connection

Gerri Frager MD

It has been some 20 years since I started working in paediatric palliative care. What propelled me into this field was, paradoxically, the exposure during my training to tragic instances involving individuals with critical illness and at the end of life. It was not the fact that these people were up against great sadness; it was that the sorrow they were facing was compounded by poorly managed pain, inadequately addressed symptoms and discommunication. It was not that the clinicians were not caring; they were ill equipped. I was left with a profound sense that we had failed these individuals, their families and the many staff who bore witness to the suffering.

I believe as physicians, when we feel that we have failed the patient, we tend to frame it in the context of not having been able to cure them of their illness, excise the tumour or treat their infection. In the setting of failing to fix the disease process, we tend not to consider other ways we may fail those we are charged to care for.

Thinking about those times, I remember the expectant mother with an absent fetal heartbeat, in advanced labour. Much like every patient I have ever known, she sensed something was terribly wrong. At her husband's and obstetrician's insistence, we cloaked her in silence and further isolated her in fear. I remember a savvy young woman with a massive and aggressive abdominal cancer. Her surgeon spoke to her about a 'mass', never describing or explaining what she was living with, despite her repeated questions. Too many times, even as recent as the days abutting my recent retirement, I would try to dispel frightening misperceptions among my colleagues, patients and family members. Treating pain or breathlessness was proposed as a choice that would help relieve the symptom but draw them closer to death. This barrier to appropriate pain and symptom management continues, despite well-documented studies that refute this association. Misconceptions abound regarding foregoing potentially life-sustaining interventions, euthanasia, pain and symptom management, and assisted suicide. I despair that even after 20 years of practice, so much confusion relating to care at the end-of-life still exists.

So, after 20 years of working in paediatric palliative care, what would I like to transfer from my head and heart to yours?

I have great respect for mining for evidence. Fear and misconceptions can propel us in unhelpful directions. I believe there is no better way to work than combining evidence with trusting your gut. If something doesn't feel right – listen to it. Find out why. Talk it over with somebody. Even if not in geographical proximity to a



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colleague with expertise in the area, these days of great technological capacity enable us to reach across oceans and over mountains for the help we need. This work can be very difficult. You are, however, not alone. I have had wonderful opportunities to present in Israel, Finland, across Canada, the United States, Europe and Australia. Regardless of location, uniqueness of culture or institution, what I have come to truly understand is that what people wrestle with most is ubiquitous. It may feel that the ethical challenges you face or the way you feel personally as a result of your professional care is unique to you. I can tell you this is not the case. I have learned that everyone feels challenged in similar ways and under similar circumstances. It is, however, not enough for me to tell you this. You must find out for yourself

that by sharing your distress with another, you will feel less alone and may be surprised at the relief this can bring.

I have learned the great value of working as part of a team. I was a nurse for nine years before I entered medicine. This background benefited me greatly in my career as a physician. We could all learn so much from one another by making the space and time to be present for one another. It is interesting that our multidisciplinary colleagues are sometimes referred to as 'allied' health professionals. They truly are our allies and it is important that we both recognize and acknowledge this.

Many people ask how I have been able to do the work that I have done. Basically, my approach is to not wrestle with the gods. I don't try to make sense of what is nonsensical. I don't try to rationalize why this is happening to an innocent infant/child/youth. Where I find comfort is to be able to provide comfort. To be able to ensure that the child and family and the staff who care for them feel that they are as well cared for as is humanly possible and that they are well supported through a most difficult time. I also realize that this is not my loss but that it, unfortunately, is theirs. At one point in my clinical work, I faced a particularly difficult time caring for two adolescents. Both of these individuals were vibrant souls, the kind of people you knew would have grown up to do great things, given the chance. One of the teenagers was at the hospital for many months and the other was cared for in their home. It was a very labour-intensive and physically demanding time, with many nights being up on call. Their care was also very challenging, requiring profoundly complex pain and symptom management. The sense of injustice hit me greater and harder than I had felt in a very long time. I became physically and emotionally exhausted. However, I did not take time or make the space

for myself. I did not consider how this care was impacting me. It was not until many months later that I carved out some time to reflect on my work and how I felt about continuing with it. I went away for a week-long retreat, talking over the challenges of work with others in a group format. It was life-changing. I was able to return to work recovered, restored and renewed. That said, I don't recommend self-care in intense blocks like this. Reflective practice and self-care should be something that is part of one's ongoing routine, similar to keeping up to date with attending conferences and reading journals.

Of everything that can bring relief or generate more distress, I believe that communication may have the greatest impact. I have found that unique approaches can provide unique solutions. I believe greater ease and depth of expression can be facilitated by integrating the arts with communication. I was sharing in the care of Donald, a seven-and-a-half-year old boy with liver cancer, and attempting to assess his pain. Despite being verbal and developmentally intact (in fact, he was precocious), Donald absolutely refused to talk with me. It wasn't until I started bringing in pictures of animals that we had any form of communication. From then on, it took off like a rocket! He would tell me about his pets at home and those he wished he could have. A conversation initially centred on animals expanded to where he would talk with me about his pain and whether he felt that he was getting enough relief from the medication, and what frightened him.

Another instance demonstrating the value of integrating the arts in health care involved a mother who was spending intense blocks of time with her son during a protracted hospitalization, awaiting transfer for his bone marrow transplant. She spoke of missing nature, particularly flowers. I brought in pictures of flowers

with which she covered the walls of his room, and she described feeling comforted by them. Another time, I prompted a family travelling to a distant centre for a bone marrow transplant to consider what picture they would bring along with them that represented 'hope'. I have used visual arts (photographs, images, and collages) in reflective exercises with residents and staff to consider what they find difficult, and help them express what serves to ground and nurture them. I have always found that when I incorporate the arts, our subsequent discussions are much richer with a greater sense of connection.

I wish each of you a rich and rewarding work life, and a happy, fulfilling personal life.

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**ACKNOWLEDGEMENTS:** I am thankful to Donald, now a thriving youth, for giving me permission to share his story.

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### **BIOGRAPHICAL NOTE: DR GERRI FRAGER**

Dr Gerri Frager is a newly retired paediatrician, having worked in paediatric palliative care at the IWK Health Centre for the past 20 years, and is a professor at Dalhousie University in Halifax. For the past five years, Gerri also directed the Humanities-HEALS Program at Dalhousie University. This translates to Healing and Education through the Arts and Life-Skills, and seeks to integrate the arts and health. Now enjoying her retirement, Gerri has returned to school as a ceramics student at the Nova Scotia College of Art and Design, and is happily pursuing the rest of her life as a full-time potter! She is now enjoying more time with her husband, Peter, at their home by the sea on the eastern shore of Nova Scotia.