Lars Björklund

I was ordained as a priest in the Church of Sweden in 1979 and I have been employed as a chaplain at Sigtunastiftelsen since the autumn of 2001. Previous employment: 22 years at Akademiska Sjukhuset (the university hospital) in Uppsala, Sweden, with ten years based in the children's ward.

The courage to be

Several years ago, when I thought of writing a book about meeting people in pain and crisis and close to death, I considered naming the book *The Art of Doing Nothing*. Early on, I had the experience that in the really difficult meetings, there was nothing to be done. All attempts to make it better or maybe bring out a positive feeling were in vain. The sorrow and the pain were too great. I still felt that it was important to be there. Not for the purpose of doing something but perhaps to lessen the loneliness a bit, in the midst of all pain.

In circumstances where it is constantly important to accomplish something, and where that which is accomplished is given the greatest meaning, a person quickly becomes lonely if there is nothing to be done. Or she might also be put through unnecessary things. What is being done, is done only for the act of doing, and this involves the risk that the person who longs only for closeness is abandoned. Another risk is that what can still be done appears worthless and is seen as nothing at all. I am thinking of such things as turning the pillow for someone who is too tired to do it themselves, to stretch out the sheet and make sure there is clean and fresh water in the glass at the bedside table next to someone who is dying. If this is all that is possible to do for another human being, then this is all you can do. To do all you can for someone is a great act, and should not be called "nothing".

Sometimes we need to do absolutely nothing, and have faith that our presence is enough. But even if we can let go of the thought to accomplish something, there can still be an unspoken wish that things will get better for the one we meet, or at least that there will be a change. I dare say there are moments when our wish can be conceived as a demand and can cause us to let down the one we meet. In certain vulnerable situations the same risk arises if we give something. In the emptiness that is born if we do nothing, want nothing and give nothing, a meeting can still take place. A meeting without expectations and demands, where a fellow human being is made visible and confirmed.

My mission is that of love, and no matter how I turn the word love inside out, I always come to the conclusion that love means to demand nothing at all. If I give love, and by the act of giving accept another person, I have fulfilled my mission. Without expectations love grows. But if I expect something in return or expect something to get better, the love can die if the answer or the improvement fail to occur. A love that expects an answer can in certain situations be conceived as a threat. But love demands no success. It is there without expectations of results and without expectations of gratitude. Redone in the difficult meeting it turns into a form of method. When I meet a person who needs help I can stay without doing anything. I can be there without giving anything else than my presence and I can leave without the expectation of gratitude. Several meetings have looked exactly like this. I could do nothing, give nothing, and I could not see any measurable result. What makes me believe that it is still important to stay are stories from people who a long, long time after a crisis realise that the one who offered the most help was the one who was there with neither demands nor expectations. Patiently and lovingly ■

Finella Craig

Finella Craig has been a Consultant in Paediatric Palliative Care at Great Ormond Street Hospital for Children since 2002. Her palliative care training included two years with a community and hospital-based adult palliative care service as well as with the paediatric palliative care team at Great Ormond Street Hospital. She has particular interests in palliative care for children with non-malignant conditions.

Paediatric palliative care

Living with a life-threatening or life-limiting condition can be challenging, particularly for adolescents and young adults as they face the physical, cognitive and emotional changes of the transition to independent adulthood. Some may have been progressing through normal adolescent development prior acute illness. For those with progressive disorders, adolescence may be accompanied by deteriorating physical health and/or mental ability. Others may be coping with lifelong chronic conditions, which may not fit easily alongside adolescent development and activities.

This presentation will explore the impact of life-limiting illness on adolescent development and how, as professionals, we can support children with life-limiting illness through adolescence to adulthood. The presentation will address issues of physical independence, independence in decision-making, financial independence, peer group identification, changing relationships with parents, sexuality and spirituality. We will discuss how, with the right support, a young person’s sense of individuality, autonomy, value and continuity can develop and be reinforced ■

Frank D Ferris MD

Frank D Ferris, MD is the Medical Director of Palliative Care Standards and Outcome Measures and responsible for the international programmes at San Diego Hospice & Palliative Care. He is a Clinical Professor, Voluntary, in both the Department of Family & Preventative Medicine, and the Department of Medicine, at the University of California, San Diego School of Medicine, San Diego, California.

Implementing quality palliative care – how to prove it

Quality palliative care is of interest to everyone who is receiving or providing care. The quality of the care that is provided depends on everyone's understanding of the underlying model that is guiding patient/family care; the organisation's mission and vision; and the consistency of the language, practice and treatment guidelines, outcome assessment and performance improvement strategies that everyone is using from day to day.

Implementation of quality palliative care within an organisation starts with careful strategic planning followed by the systematic development of guidelines, outcome measures, standards and a performance improvement process through an inclusive consensus-building process. By modifying existing widely-accepted models, organisations can expedite their implementation of quality palliative care. Through careful attention to evolving this process over time, everyone will be the benefactors of a high-quality palliative care experience.

This plenary presentation will focus on the process and the potential outcomes/benefits for key stakeholders ■

Katalin Muszbek MD

Katalin Muszbek MD, psychiatrist, psychoanalyst, Director and founder of the Hungarian Hospice Foundation, Vice-president of the board of the Eastern and Central European Palliative Task Force and member of the International Psycho-oncology Society.

Cultural issues in facing death

Individual and social attitudes relating to reaction for loss have been undergoing significant changes during the last decade. The aftermath of loss depends on various conditions. The presentation separates the role of traditions and psychological aspects of the individual while it also touches the role of palliative care.

1. Social attitudes: attending to a dying person in traditional cultures relies on both the family and the society while in the developed world individual autonomy is dominant. Formerly it was the community, the rituals and the traditions that helped facing death. In traditional communities mourning was not only accepted, but it was an expected form of behaviour associated with numerous rituals.

   By today the majority of these traditions have ceased and the attitude system of the society regarding death and bereavement have also undergone changes.

   Effective bereavement today means rapid mourning process, few personal reactions and an early back-to-normal lifestyle.

2. The individual psychological reactions depend on personality structure. Coping and defensive mechanisms in facing death and loss processing both vary with the individual. It is important to analyse aggression and remorse handling linked to loss as well as the role and the consequences of suppression.

3. Healers – enchanters, shamans and doctors are omnipotent people helping us to cope with illnesses and symptoms. Cultural differences in this area are substantial but the omnipotent saver is a determinative personality in all different cultures. In today's modern societies this mission is completed through palliative care. The need for it is universal, regardless of frontiers and nations ■