

Long, drawn out terminal illnesses present their own unique grief challenges. The very names of diseases, such as Cancer, Alzheimer, Parkinson, or AIDS for example, strike terror in our hearts because of the suffering and mortality they often conjure up. Cancer, for example, will be experienced directly by one out of four persons and one out of two of these will die from it. But its effect does not end here. Still many more family and friends will be touched by those people living with cancer and so on. Resources, professionals, institutions, energy, and finances, will also be drawn into the struggle with this disease. Education is important as are research and healthy life styles. Likewise, many medical and scientific gains have been made in this area. Some forms of cancer are curable, especially if caught early, but there are so many different types of cancer that we still remain anxious. Some treatments are conventional and others unconventional. Stories of long time survivors bring us hope, while deaths of friends and acquaintances reminds us of fatality. Such is part of the backdrop that we encounter in dealing with grief issues unique to such long term illnesses.

Sometimes there may be a lot of emotional and psychological pain attached to seeing and caring for a person who slowly deteriorates and changes from a strong vibrant person to a weakened, pale shadow of their former self. Likewise, it is painful to think that our loved one may be experiencing actual physical distress. The deterioration evidenced can leave the family feeling useless and helpless, especially when the dying person does not even recognise their own spouse or children. Modern medical treatment goes a long way to controlling with pain medication the physical suffering and symptoms. Likewise, a total approach by the medical and care-giving team ensures that many of the non-physical needs are also met.

There is a positive outcome of much of the newer directions in health care with its stress on the individual. Movements such as palliative care and hospice make the individual and their family the centre of medical care and not the illness. This stress on the individual rather than the disease is a healthy perspective that reflects the dictum of William Osler: "The person who has a disease is more important than the disease a person has". The philosophy of palliative care is to provide pain control and stabilisation and its approach is multi-disciplined. Likewise, hospice carries on the palliative care mandate by providing a haven where people may live with their disease in a positive, life-affirming way, that celebrates their relationships and worth. The emphasis is on living and not dying, on enjoying the time left and not bemoaning it.

With a long term illness there is the 'benefit' of time for both the person living with the disease and the family and friends supporting them. This is 'advantage' or 'gift' of time allows anticipatory grief to begin and the putting closure and the letting go become positive activities that all relationships can be directly involved in. By anticipatory grief we refer to the fact that many of the same stages that happen in the bereavement process often begin earlier while the loved one is still alive. There is still much debate about the state of anticipatory grief but enough is known to assert the reality that it plays a therapeutic role in the overall bereavement process. The past and the present are also grieved, as well as the future There is even the beginning of a future detachment,

not from the present care of the dying person, or with the past remembrances, but rather with the coming reality and understanding that the loved one will not be around to be part of such activities. It is still a shock when the eventual death occurs, but much less so than in the a situation of sudden loss or unexpected death.

This time also provides opportunity for families to express their love, resolve unfinished business, and say their farewells. Practical realities such as a will, advanced directives, assigning of special objects to different family members, and sorting out one's affairs can actually contribute to the peace of mind of all concerned and very practically avoid later legal and financial confusion. As well, funeral arrangements, organ donation designations, celebrating and affirming family relationships and friendships, are all part of the opportunity that such a longer term of time affords. One of the worse feelings that occur after a death is that of helplessness. The time afforded in a long term illness allows everyone 'to do' something positive for their loved one; this is perhaps why such a period is so valuable.

Finally, if we are people of faith, we are able to turn to our beliefs for comfort, meaning and support. Prayer, scripture, meditation, and one's religious community and clergy can give a peace that transcends suffering and pain. Ultimately one of the strongest drives experienced is the drive for meaning. Within the mystery of tragedy, suffering and pain we learn to say yes to life and love.

A long term death can be painful but the discomfort is tinged with the value of the grief work that can occur during such a time if positively engaged. In truth, grief after a long term illness will be greatly modified by the bereavement work done during the illness by all involved.

Community Resources

Depending on your locale, some support sources may not be present. A family doctor, mental health centre, hospital, social worker, counsellor, clergy or your funeral director can assist you with an appropriate referral in these cases.

ARK - Counsels children and teenagers who have experienced the loss of a parent through death or divorce

HOSPICE - Supports the dying person and their family, before, during and after a death.

W.H.O. - Widows Helping Others - On-going support group

Suggested Reading

There are many books available on this topics. The following are a few that I recommend.

Carroli, D. Living with dying: A loving guide for family and close friends, McGraw Hill, 1985.

Freese, A., Living through grief and growing with it, Barnes & Noble Books.

Grollman, Earl A. Time Remembered: A Journal for Survivors. Boston: Beacon Press, 1987.

Kushner, Harold. When Bad Things Happen to Good People. New York: Schocken, 1981.