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## LOVE, ALWAYS

Lessons from the Dying on the Meaning of Life ©Clairview Books 2015

Translated from Italian by Patricia Brigid Garvin

## **INTRODUCTION**

My first encounter with death occurred over fifty years ago when my grandmother Alice died. I had almost finished university and was still living with my parents and my sister. My grandmother was a fat, robust woman, strong-willed, dynamic, intelligent, cheerful, independent and unconventional. She was a very important presence in my life and I loved her dearly. When my grandmother became ill five years before she died, she came to live in our home, where my mother cared for her with a dedication that was exemplary. As the illness took hold, my grandmother gradually gave up the countless activities that had filled her days, and her horizon eventually narrowed to the close family circle and her dream of a princely wedding for my sister. My grandmother died in my mother's arms: she was combing my grandmother's hair in readiness for her visit from the Waldensian pastor, her spiritual companion during her last days.

As a volunteer in the department of palliative care<sup>1</sup> at a Brussels hospital in the years since my retirement, I've come to realise that a peaceful death in an atmosphere of affection and spirituality is not an exceptional experience. Terminally ill patients are accompanied to the end of their lives with their pain relieved in a context of human relationships, respect and dignity.

Palliative care is the new face of medicine; it incorporates scientific and technological progress while acknowledging interpersonal relationships and the integrity of the person in his or her various dimensions: physiological, mental, emotional and spiritual. It is a new form of medical care that goes

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<sup>&</sup>lt;sup>1</sup> For palliative care in Italy, Belgium, France, and the UK, see Appendices 1 to 4 on pages 119 and followings.

beyond the concept of the hospital business model, in which machines are run to correspond to a balance sheet, and where quality is synonymous with productivity rather than humanity.

Assisting the dying has led me to reflect upon how the perception of the passage of time is relative for we who believe ourselves healthy and immortal, compared with those who are conscious of the inexorable imminence of their death. The value the terminally ill give to their remaining days helps me to decide how to use my time before it's too late, giving me the chance to come closer to an understanding of the meaning of my life, to be aware of my vulnerability, and to prepare myself with serenity for my own death.

At one time, there was greater familiarity with death, which was part of everyday life due to the high infant mortality rate and the tighter family units that included three or four generations. Today's changing health and social conditions, together with medical advances and the new role of the hospital, have distanced and marginalised death to the point that when a relative of ours is dying we are unable to admit that the illness is terminal. In a vain effort to protect, we seek to hide the truth from our family members without even trying to discover whether or not they wish to be told clearly.

I know that I must die. I know that everyone dies sooner or later, yet it's as though I don't believe it and behave as if I were immortal. Even many doctors behave as if they do not consider death to be the natural and inevitable conclusion to existence. They see death as the failure of their efforts and the defeat of medicine, and so they persist in senseless therapies to the bitter end, even if these only lead to a continuation of suffering.

But does death exist? Perhaps not. Perhaps it is only our reception into another world — a mere transition,² but one that frightens us: we are afraid of physical pain and of our loss of status and self-esteem in the terminal phase of life. But this fear should not cause us to behave as though we were dead before we really are.³ We should establish ourselves definitively in the world before we disappear.⁴ The problem is not so much knowing if there is life after death as it is of living before we die,⁵ and the technological advances of medicine should not turn the role of therapy into one of adding empty days to a life left without personal relationships, but should instead add life to the days that remain for us to live.

<sup>&</sup>lt;sup>2</sup> Lucius Annaeus Seneca, Mors ant finis ant transitus in Epistole morali a Lucilio (Dante Alighieri, Rome, 2007) n. 65, quoted by Ivano Dionigi in Massimo Cacciari, Ivano Dionigi, Alberto Mallian, Gianfranco Ravasi, Silvia Vegetti Finzi, Morte, fine o passaggio?, Rizzoli, Milan, 2007, p. 9.

<sup>&</sup>lt;sup>3</sup> Maurice Zundel, quoted by Marie de Hennezel, *Mourir les yeux ouverts*, Albin Michel, Paris, 2005, p. 73 Marie de Hennezel, *La mort intime. Ceux qui vont mourir nous apprennent à vivre, Morte, fine o passaggio?* Laffont, Paris, 1995, p. 207.

<sup>&</sup>lt;sup>4</sup> Michel De M'Uzan, De l'art à la mort, Gallimard, Paris, 1983, pp. 182-199.

<sup>&</sup>lt;sup>5</sup> Hennezel, La mort intime, cit. p. 207.

This book is a testimony narrated via stories inspired by my current volunteer activities in a hospital, and by personal encounters with suffering and death. It was also written out of a need to communicate emotions and experiences too intense for me to keep inside, even if in some cases it took many years before these emotions could be expressed and shared.

The names of the healthcare providers are fictional, and I assume all responsibility for the thoughts they express since these have been conceived according to my own personal views. I have learned a great deal from the ward's doctors and nurses, and have been inspired by their humanity, their sensitivity, and the richness of their diversity. Dr. Charles does not exist. He is the doctor I would have liked to have been. Similarly, I have introduced other characters, such as Tunç, Émile and Angela, in order to narrate certain episodes of my life.

The names of the patients and their personal circumstances have been altered to avoid revealing the private lives of those who have honoured me with their confidence. However, I did not feel the need to alter the names of my parents, or of certain other people whom I attended until their death, because my relationship with them is too deep to be hidden by a literary fiction. Indeed I feel I have their permission to call them by name and recount their lives without revealing any secret, because when I speak of them I am speaking of myself and nothing is invented; everything is inspired by what is experienced and suffered in the mysterious proximity to death, which in the end means drawing closer to the truth and to eternal life.