# مبادرة لبدء الرعاية التلطيفية لمرضى الأورام فى مصر

رسالة مقدمة من الطبيب

**رضا صموئيل رزق الله**

توطئة للحصول على درجة الماچيستيرفي علاج الألم

تحت إشراف

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**٢٠١٠**

# SETUP FOR INITIATION OF PALLIATIVE CARE FOR CANCER PATIENTS IN EGYPT

Essay submitted in fulfillment of the
Master Degree in Pain-Relief

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## Key Words

Palliative Care, Hospice, Hospice Care, Pediatric Palliative Care, Advanced Cancer, Comfort Care , Care of the dying or terminally ill cancer patient, End of Life Care, Life Limiting/Threatening illness, Progressive Terminal Illness, Respite Care, Supportive Care, Symptom Management, Terminal Cancer, Terminal Care

## Abstract

"Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems: physical, psychosocial and spiritual".

(World Health Organization, 2002)

At present, the implementation of palliative care and patients' access to it are inconsistent across many parts of the world, including Egypt.

This essay aims to introducing the principles of Palliative and End of Life care to health care professionals treating cancer patients (adults and children) in Egypt. It aims to help them, initiate and recognize the different models for delivering this type of care, to improve the quality of life of cancer patients; and enable them to manage pain and symptoms through evidence based techniques and interdisciplinary holistic approach of cooperating teams, since the current concept among oncologists is restricted to palliative chemotherapy, palliative radiation or hormonal therapy.

DEDICATED
TO THE MEMORY OF
MY MOTHER,
MY BROTHER RAGAÏ,
PROFESSOR OMAR TAWFIK,
PROFESSOR FATHY NASR
AND
TO ALL CANCER PATIENTS

> “WE HAVE BEEN CREATED
> TO LOVE AND TO BE LOVED"
>
> **Mother Teresa of Calcutta**

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Professor Magdi R. ISKANDER, made also grow in me the art of Palliative Care and Pain Relief, the sense of compassionate care and the desire to alleviate the suffering of our fellow brothers and sisters cancer patients.

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The Candidate.

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In developed and developing countries alike, most cancer patients (adults and children) are living and dying in unrelieved pain, with uncontrolled physical symptoms, unresolved psycho-social and spiritual problems, in fear and loneliness. At the same time, many of these patients die with unnecessary and untreated suffering. Many of them may want or need to discuss their psychological, social or spiritual concerns, while others may not. Most of their concerns are: pain, fears about the future, loss of independence, worries about the family, and fears of being a burden. This fact is well documented in many studies and published in hundreds of scientific papers and reports.

(National cancer control program, WHO, 2002)

In spite of all the recent advances in cancer treatment, many cancer patients ultimately die after suffering from their disease. Palliative care is the comprehensive and global attention to pain, symptoms, psychological suffering, social needs and existential distress of patients who face life threatening illness, with limited prognosis, like cancer, in order to optimize their quality of life and that of their families or close friends.

(Ahmedzai et al, 2004)

Unfortunately, Palliative Care is still missing in many countries where a high proportion of cancer patients are diagnosed in advanced stages and treatment is no more effective. It is estimated that each year 7.8 million people die worldwide from cancer, with unrelieved suffering. We already know that the number of new cancer cases each year will be rising, from 10.9 million in 2002 to 16 million in 2020, with nearly a 50% increase.

(Global Action Against Cancer, WHO and UICC 2005)

At present, the implementation of palliative care and patients' access to it are inconsistent across many parts of the world, including Egypt.

# AIM OF THE ESSAY

This essay aims to introducing the principles of Palliative and End of Life Care to health care professionals treating cancer patients in Egypt. It aims to help them, initiate and recognize the different models for delivering this type of care, to improve the quality of life of cancer patients; and enable them to manage pain and symptoms through evidence based techniques and interdisciplinary holistic approach of cooperating teams, since the current concept among oncologists is restricted to palliative chemotherapy, palliative radiation or hormonal therapy.

## Glossary of Terms

**Comfort care :** a term sometimes used as synonym for palliative or hospice care as it is more understandable and acceptable to patients and their families.

**Care Conference:** A formal or informal meeting of health care professionals involved in the care of a patient to communicate and/or develop the plan of care. The patient and family are not present.

**Family Conference:** A meeting among the patient, family and health care team to facilitate communication about the plan of care, discuss the patient / family goals and resources and the transition or discharge plan.

**Caregiver:** the closest person to the patient e.g. the spouse, adult child, parent or friend. He/she provides for the needs of the patient and takes on additional technical tasks of care e.g. administration of medications.

**Care of the dying:** care of the patient and family in the last hours and days of life. It incorporates four key domains of care: physical, psycho- social and spiritual. It supports the family at that time and into bereavement.

**Children's hospice:** a term to describes both a place and a philosophy of care for children with life-threatening diseases.

**Complementary Therapies:** Therapies, which are applied in adjunctive fashion to reduce pain and other symptoms. They are non-invasive and include aromatherapy, reflexology, hydro-therapy, art therapy, music therapy and others.

**Complex Continuing Care:** a package of care beyond what is available through core and universal health services. It is provided to patients with high levels of complexity or intensity of nursing care needs.

## GLOSSARY OF TERMS

**Family:** The family is defined as those who are closest to the patient in knowledge, care and affection .The family may include the biological family , the family of acquisition (related by marriage/adoption), and the family of choice and friends .

**Good Death:** is a decent death free from avoidable distress and suffering for patients, families and caregivers.

**Grief and Bereavement**

Grief: is the term usually used to describe people’s normal feelings and behaviors in response to death of a loved person (e.g. sadness, numbness, anger, sleep disturbances, inability to concentrate and fatigue). Research suggests that death of a child prompts more intense grief than death of a parent or spouse.

Anticipatory grief: grief that occurs in advance of an expected loss. Such losses may include not only death but also losses of expectations for a “normal” life (e.g. diagnosis of a child’s serious physical or cognitive disability). Anticipatory grief is also experienced by children and their parents.

Bereavement: describes the situation or fact of having experienced loss through death rather than to the emotional content of the experience.

Complicated grief or bereavement: refers to a response to loss that is more intense and longer in duration than usual. Although bereavement is a term usually applied to family members, feelings of grief may be shared by many others who have known the child or who feel close to the family. The physicians, nurses, and others who care for a child who dies may grieve, whether or not they feel able to express it.

Mourning refers to the social rituals and expressions of grief and sometimes to the psychological process of adapting to a loss.

## GLOSSARY OF TERMS

**Hospice:** (from the same linguistic root as “hospitality”) is a term used interchangeably to describe a philosophy, a program of care, or a site of palliative care. In this work, hospice refers to an organization or a program that provides, arranges and coordinates, palliative care.

Hospice at home: a term commonly used to describe a service which brings skilled, practical palliative care into the home environment. Hospice at home works in partnership with patients and families and provides expert nursing care, on a 24-hour basis.

Hospice care: a service delivery system and a philosophy of care that provides palliative care for patients who have a limited life expectancy and require comprehensive physical, psychosocial, and spiritual support as they enter the advanced stage of an illness or condition.

**End of life:** the phase of life of a patient when his/her illness worsens and eventually causes death.

End-of-life care: is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die.

**Life-Threatening and Fatal Conditions:**

Life-limiting (shortening ) illness or fatal medical condition: a progressive illness for which there is no reasonable hope of cure and from which the patient's life will be shortened and death will occur prematurely as a direct consequence. It includes malignant and non-malignant diseases. It differs from chronic illness where, even though there may be significant impact on the patient’s abilities and quality of life, there is a less direct relationship between the illness and the person’s death .

Life-threatening conditions: Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer. Patients in long-term remission or following successful curative treatment are not included.

# FOREWORD :

# GLOSSARY OF TERMS

**Palliative care:** Palliative care (from Latin **palliare**, to cloak) is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms rather than striving to halt, delay, or reverse progress of the disease itself or provide a cure. It is the active total care of patients and their families by a multidisciplinary team when the patient's disease is no longer responsive to curative treatment.

Palliative Approach: an approach linked to palliative care that is used by primary care services and practitioners to improve the quality of life for individuals with a life limiting illness, their caregiver/s and family. It incorporates a concern for the holistic needs of the patients and caregiver/s.

Palliative Care Team: A multi-disciplinary team with some or all of the following: physicians, nurses, social workers, chaplains, psychologists, pharmacists and dieticians. All of them, work together in an interdisciplinary manner and are certified or trained in palliative care.

**Patient with a life limiting illness:** the primary recipient of palliative care.

**Primary caregiver:** the person who provides primary support for the patient at all levels of need .The term primary caregiver may include more than one individual, for example the mother and father when the patient is a child .

**Progressive terminal illness:** the point where nothing more can be done to cure someone.

**Respite care**: provision of care by appropriately trained individual(s) for patients with life-limiting conditions, for a specified period of time, thus providing temporary relief to the usual care-giver and family. It may take place in the patient's home or in a setting outside of the home such as a hospital, long-term care facility or hospice.