

# Multidisciplinary Cancer Management Course

## Palliative Care

**Towards availability of a nationwide coordinated palliative care program for cancer patients in every Country.**

A call from “**ICEDOC’s Experts in Cancer Without Borders**” & **SEMCO (South and East Mediterranean College of Oncology)** on the occasion of the ASCO-SEMCO Multidisciplinary Cancer Management Course  
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& from **SEMCO & ICEDOC's Experts in Cancer Without Borders**  
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# Multidisciplinary Cancer Management Course

## ICEDOC: INTERNATIONAL CAMPAIGN FOR ESTABLISHMENT AND DEVELOPMENT OF ONCOLOGY CENTERS

(A non profit organization registered in USA)

(Main corpus: **ICEDOC's Experts in Cancer Without Borders** )

(Website [www.icedoc.org](http://www.icedoc.org) )

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This presentation doesn't represent only the speaker here, but it is a call from ICEDOC, particularly its Palliative and supportive care group :

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Scientific Advisor for Palliative Care : **Robert Twycross** (UK).

ICEDOC is also an associated member in **INCTR** (Belgium) and **AORTIC** (African Organization for Research and Training in Cancer) . Moreover, ICEDOC is a worldwide associate member in the UK Forum for Hospice and Palliative Care.

& Recently with **SEMCO** (South and East Mediterranean College of Oncology)

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In this presentation , **ICEDOC** doesn't claim that we could offer full detailed ideal palliative care programs.

The approach of **ICEDOC** , is always to outline some main points , to present some suggestions and to raise stimulating points that could finally crystallized by the **local** competent and knowledgeable experts and colleagues.

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**The local colleagues, everywhere, are finally the best who can tailor and implement realistic, but ambitious nationwide palliative care programs that better allocate resources and consider local problems.**

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- With a wise global cancer approach, **the beneficial results** achieved must **be balanced against the harmful effects** of the treatment.
- With all respect to Pharmaceutical industries, **we should not be just pharmaceutical companies oriented in our prescriptions.**  
**Evidence based medicine** should be considered.

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In developed countries, **at least two thirds of patients** are in need of **one or more sorts of palliative and supportive care** during the course of their disease. This is despite of all recent advances in cancer treatment modalities.

The problem **is graver** in countries with limited resources spent in health programs.

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- Palliation is a term defining an **intention** rather than a single specific treatment. **It is not a synonym of pain killer (nor simply morphia !)**.
- However, the successful control of pain is **one** of the **main problems and priorities** that should be much considered. Legislation, pain clinics and availability of pain killers including narcotics in an organized environment are essential for patients to whom these drugs are medically prescribed (**Palliation of pain is a divine work, Gallen, in the 2<sup>nd</sup> Century**).

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- Palliative care is defined as the **“active total care for patients whose disease is not completely cured”**

- Dignity of patients and their families should be one of the objectives till the last moments.

Those patients or their families could be us, in any moment of the life!

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- **Palliative care could start from the moment of final diagnosis or even before !**
- **Dignity, culture, beliefs and financial burden of patients and family should be considered.**

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- We raise here , the problems of some ambiguity about the terminology and goals of the term “Palliative Care” **versus** the term “Terminal Care” with its Psychological barriers.
- The terms “Palliative Care” and “Terminal Care” are not synonymous.
- “Palliative care” aims at restoring an acceptable quality of life . It may lasts for months or years. **While** the “Terminal Care ” regards the quality of death. This care is provided in the last few hours or days of life.

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- We Should remember “ caring of the dying is also caring for the livings”
- In **ICEDOC** we think that calling **wrongly** the whole phase of palliative care as “Terminal Care ” Or “End of life care” may diminish the care we are trying to give in palliative programs.
- Hence , **we** think that it may be better to refer to the **terminal care** as **only** this very particular **last part of palliative care programs**. The part that come at the last few hours or days of life , with all particularities of this critical period and its care

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- Palliative care may last for few **months** or **years**. **Many patients may live with reasonable (Or acceptable ?) quality of life .**
- Despite of the **importance of palliative and supportive care** ,unfortunately, most resources **are devoted to expensive** (curative ?) treatments , and in **many occasions without** realistic or expected curative intention .

**There is a little attention to an organized and rationale palliative care and training of health staff !!.**

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- **Public awareness and Media involvement are needed but in explanatory, assuring and well trained approach**
- **Palliative care are composed of multi-professional tasks .**

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## The main five dimensions of palliative care are :

Care for the **patients** :

1) Bio-Physical.

2) Psycho-social.

3) Spiritual.

• Care of- and for- the **caregivers** :

4) the Staff.

5) the family.

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According to Dunlop GM (Palliative Medicine 1989; 4: 37- 43), the most 12 common symptoms are:

<b>Weakness</b>	<b>82%</b>	<b>Dry mouth</b>	<b>68%</b>
<b>Anorexia</b>	<b>58%</b>	<b>Depression</b>	<b>52%</b>
<b>Insomnia</b>	<b>46%</b>	<b>Pain</b>	<b>46%</b>
<b>Swollen legs</b>	<b>46%</b>	<b>Nausea</b>	<b>42%</b>
<b>Constipation</b>	<b>36%</b>	<b>Vomiting</b>	<b>32%</b>
<b>Confusion</b>	<b>30%</b>	<b>Dyspnea</b>	<b>30%</b>

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Moreover, there are important problems such as :

**Fear and anxiety,**  
**Mouth care,**  
**Diarrhea,**  
**bladder pain,**  
**Fungating lesions,**  
**Incontinence,**  
**Lymphoedema (e.g. arm edema)**  
**Cough.**

**Eating and feeding,**  
**Intestinal obstruction,**  
**Recto-vaginal fistula,**  
**Itch,**  
**Confusion,**  
**Skin problems,**

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## Palliative measures:

- In Palliative medicine, measures may vary from reassurance, sympathizing ear, or analgesic to specific measures like surgery, radiation or chemotherapy.
- A combination of general and specific measures is usually necessary. It should be individualized and tailored to each patient.

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## Main palliative measures

- A) General
- B) Specific
- C) Combined : which is the most common.

### A) General :

- Mental and emotional welfare (Moral).
- Nutritional support.
- Control of non specific symptoms associated with the main disease – cancer or chronic illness – or its treatment e.g. nausea, vomiting, constipation, diarrhea, dermatitis, **pain ( the WHO Analgesic step ladder : Non opioids, then Weak opioids, then up to strong opioids when indicated)**

## Main palliative measures (cont'd)

### B) Specific:

- **Surgery:**

e.g. Excision of recurrent masses, relief of obstructions (e.g. colostomy), relief of pain (e.g. nerve resection), or fixation of pathological fractures.

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- **Radiotherapy:**

- In general about two thirds of cancer patients would need radiotherapy along the course of the disease.
- **Example of palliative radiotherapy:** In cases of secondaries of Bone and brain, Spinal compression, recurrent neoplasm, reducing mass of a tumor, its pressure symptoms or fungation .
- Radiotherapy may be combined with chemotherapy or preceded or followed by palliative surgery .

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- **Chemo and hormonal therapy of cancer:**

The **beneficial results expected** should be balanced against **the physical side effects** and **financial burden**. Hence, the total beneficial outcome and quality of life is considered.

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## Where ? :

Different palliative care have been developed in some countries, but the *choices of the place of palliative care should be tailored according to each country resources, patients and problems:*

- **Home Care**: Experts consider that, **whenever possible, the home is the best place** to take care of advanced patients. However, the dedicated caring relatives and the availability of visiting trained nursing and health personnel are not guaranteed for all cases
- **Inpatient care** : Hospices and palliative care units.

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## Where ? : ( Cont'd )

**Consultation services** : Small teams, usually of a physician, expert nurses and social workers can provide specific consultation for different wards and hospitals.

- **Day -hospice**
- **Bereavement support**: Trained health personnel, usually social workers and volunteers, may help relatives to cope with bereavement.

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## The Palliative care givers :

- The Family .
  - The Staff.
- Educational programs and good preparation of the caregivers are mandatory.
  - It is of **extreme** importance to pay attention to care about the Staff care givers themselves, their condition of work and living, the continuous professional education and the support offered to them.

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## The Staff

1. General Practitioners (**family doctors**)
2. Palliative care consultants
3. Nurses
4. Consultant surgeons
5. Consultant oncologists
6. Pain killers experts (or pain clinics)
7. Physiotherapists
8. Occupational therapists
9. Social workers
10. Psychologists, psychiatrists,
11. Home helpers and assistants,
12. Spiritual help provider or counselor
13. Others.

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## Here, we stress on some main points :

- Patients and family oriented care **is a holistic approach** that focus on patients goals, beliefs and expectations.
- There are palliative cares for **adults, elderly patients and for children**. The care of children with cancer and severe chronic illness have its particularities for ill children, their families and caregivers.
- Can we create **“Coping Strategies”** for families whose member has cancer?

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We stress on some main points : (Cont'd )

- Can **we come together**, (health authorities, health professionals, cancer departments and centres, university hospitals, community resources) in order **to pool knowledge, facilities and resources and to create a wide campaign for palliative care for all who are in need** (Most of us sooner or later !).?
- Public awareness and Media involvement are needed but **in explanatory, assuring and well trained approach**. **Can we succeed in this ?** .

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We stress on some main points : (Cont'd )

- Can we Succeed to include **palliative care** in the **integral health system** ?
- Can we succeed to include **palliative care** in the **educational programs** for undergraduates and postgraduates studies of medical and nursing faculties and in continuous professional education programs?

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We stress on some main points : (Cont'd )

- Can health authorities, hospital managers, the medical community and public **be aware finally, that Oncology Institutes, departments, and surgical units are rarely the right place for palliative care** except to perform short specific measures, when indicated in some cases.?

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- Can we translate researches into practice, and subject practice to researches **in order to create evidence based palliative care guidelines that should be tailored to every particular community AND NOT IMPORTED ?**
- Can we translate words and wishes into programs and implementation?
- If you are convinced, and if you agree, then let us go forward together from here... starting with **Education**.
- **Let us consider developing this topic as one of the objectives of SEMCO and Alliances.**

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Once again, we stress on that **The local colleagues**, every where in every country, are finally **the best** who **can tailor and implement realistic**, but ambitious, nationwide **palliative care programs** that better allocate resources and consider local problems.

Hence, **What we can offer** is **education** and **to help in developing programs** with the guide of the local colleagues who finally adapt what fits their community and patients.

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Till our next SEMCO & Alliances meetings.....  
Wishing you more progress and warmest  
regards on behalf of all colleagues in  
SEMCO..... Thank you !

**( Don't miss the website [WWW.ICEDOC.ORG](http://WWW.ICEDOC.ORG) )**

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## End-of-Life Care

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Slides prepared by  
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Adapted from the Education in Palliative and  
End-of-life Care for Oncology (EPEC-O) Curriculum

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## Preparing for the End of Life

- Timeline of end stages unpredictable
- Privacy and intimacy important
- Anticipate need for medications, equipment, and supplies
- Prevent surprises
- Regularly review the plan of care with the patient, family, and caregivers

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## Physiologic Changes During the Dying Process

- Increasing weakness and fatigue
- Decreasing appetite and fluid intake
- Decreasing blood perfusion
- Neurologic dysfunction
- Pain
- Loss of ability to close eyes

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## Weakness and Fatigue

- Decreased ability to move
- Joint-position fatigue
- Increased risk of pressure ulcers
- Increased need for care
  - Activities of daily living
  - Turning, movement, and massage

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## Decreased Appetite and Food Intake

- Family fears: “giving in” and/or starvation
- Reminders
  - Food may be nauseating
  - Anorexia may be protective
  - Risk of aspiration
  - Clenched teeth express desires, control
- Help family find alternate ways to express care and love for the patient

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## Decreased Fluid Intake

- Oral rehydrating fluids
- Family fears: dehydration and/or thirst
- Reminders
  - Dehydration does not cause distress
  - Dehydration may be protective
- Parenteral fluids may be harmful
  - Fluid overload, breathlessness, cough, and secretions
- Mucosa and conjunctiva care

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## Decreased Blood Perfusion

- Tachycardia, hypotension
- Peripheral cooling, cyanosis
- Mottling of skin
- Diminished urine output
- Parenteral fluids will not reverse

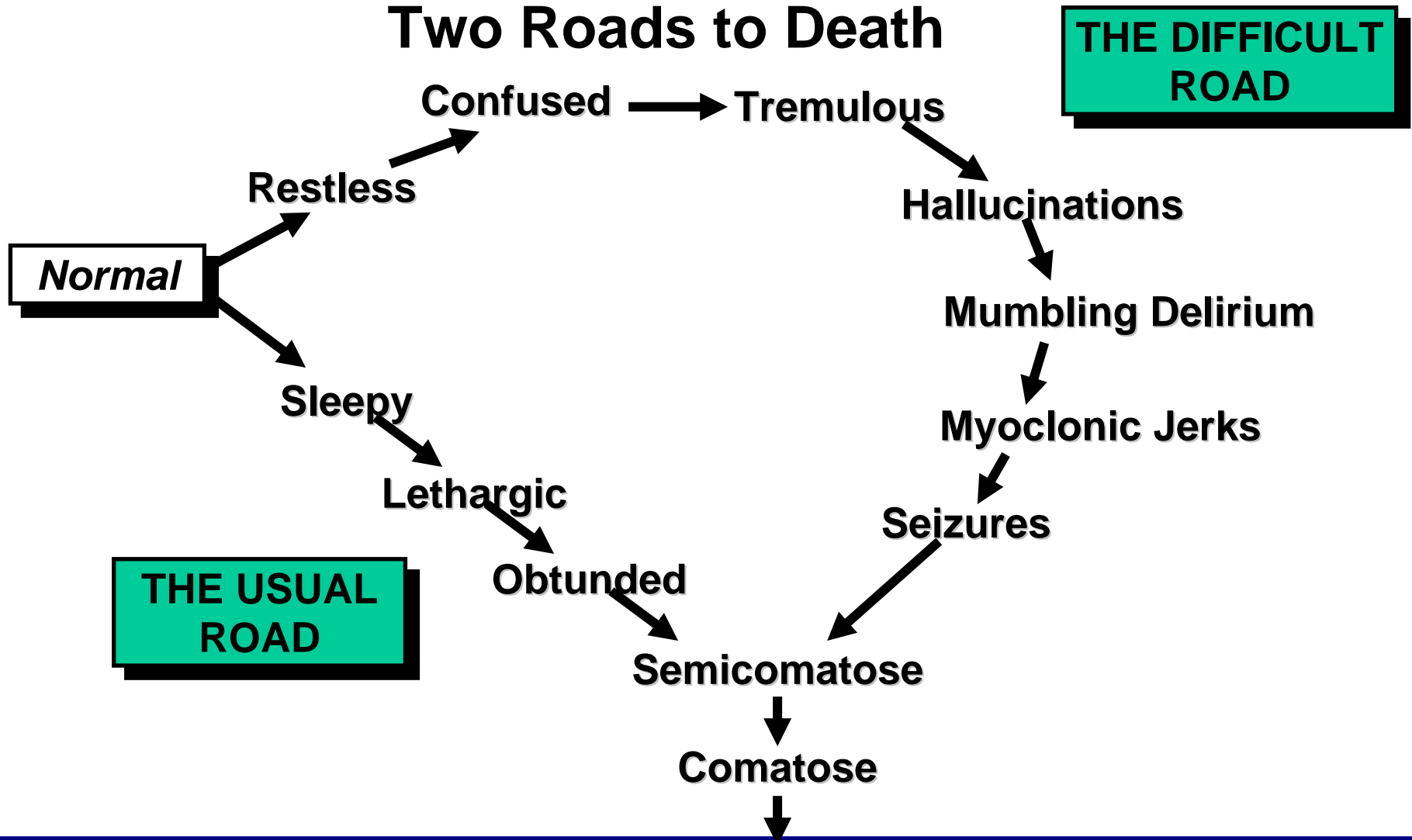
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## Neurologic Dysfunction

- Decreased level of consciousness
- Communication with the unconscious patient
- Terminal delirium
- Changes in respiration
- Loss of ability to swallow and to control sphincter

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## Two Roads to Death



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## Decreasing Level of Consciousness

- “The usual road to death”
- Progression
- Eyelash reflex

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## Terminal Delirium

- The “difficult road to death”
- Family needs support, education
- Seizures

### Medical management

- Benzodiazepines
  - Lorazepam, midazolam
- Neuroleptics
  - Haloperidol, chlorpromazine

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## Changes in Respiration

- Altered breathing patterns
  - Diminished tidal volume, apnea, Cheyne-Stokes respirations, accessory muscle use, last reflex breaths
- Fears
  - Suffocation
- Management
  - Family support
  - Oxygen may prolong dying process
  - Low doses of opioids or benzodiazepines for breathlessness

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## Loss of Ability to Swallow

- Loss of gag reflex
- Accumulation of saliva, secretions
  - Scopolamine to dry secretions
  - Postural drainage
  - Positioning
  - Suctioning

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## Loss of Sphincter Control

- Incontinence of urine, stool
- Family needs knowledge, support
- Cleaning, skin care
- Urinary catheters
- Absorbent pads, surfaces

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## Pain in the Last Hours of Life

- Myth of increased pain with dying
- Assessment of the unconscious patient
  - Sustained grimace, behaviors
  - Persistent versus fleeting grimaces
  - Incident versus rest pain
  - Distinction from terminal delirium
- Management when there is no urine output
  - Stop routine dosing, infusions of morphine
  - Breakthrough dosing as needed
  - Least invasive route of administration

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## Loss of Ability to Close Eyes

- Loss of retro-orbital fat pad
- Insufficient eyelid length
- Conjunctival exposure
  - Increased risk of dryness, pain
  - Maintain moisture

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## Medications

- Limit to essential medications
- Choose less invasive route of administration
  - Buccal mucosal or oral first, then consider rectal
  - Subcutaneous, intravenous rarely
  - Intramuscular almost never

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## Dying in Institutions

- Home-like environment
  - Permit privacy, intimacy
  - Allow for personal items, photos
- Continuity of care plans
- Avoid abrupt changes of settings
- Consider a specialized unit

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## As Expected Death Approaches

- Discuss
  - Status of patient, realistic care goals
  - Role of physician, interdisciplinary team
- Reinforce signs, events of dying process
  - Translate what onlookers see into what patient is experiencing
  - Personal, cultural, religious, rituals, funeral planning
  - Family support throughout the process

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## Immediate Time of Death

- Verify absence of heartbeat, respirations
- Confirm details of death
- Explain pronouncement process to family members
- Perform pronouncement
- Document for medical record

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## Bereavement Care

- Attendance at funeral
- Condolence notes

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## Summary

- End-of-life care is as important as any other time in cancer care
- Management principles are the same for at home or in a health care institution
- Family members and other caregivers should be informed about what to do and what to expect
- Care for the family does not end with the patient's death