

Principles of Palliative Care

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Providing care

Enhancing dignity



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Anatole Broyard

literary editor NYT

“To the typical physician, my illness is a routine incident in his rounds while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity . . . I just wish he would . . . give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.”



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Definition of dignity

- ❖ A sense of being worthy of esteem or respect
- ❖ How we are treated (dealt with) impacts on self-esteem and self-respect
- ❖ Sense of self-worth
- ❖ Sense of being a burden on others



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Dame Cecily Saunders

“ You matter because you are you,
and you matter to the end of your life. We
will do all we can not only to help you die
peacefully, but also to live until you die.”



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“ One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.”

Francis Peabody, 1927

Medical professor, Harvard University



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Broyard

“I’d like my doctor to scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness.”



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WHO Definition of Palliative Care

Palliative Care is an *approach* that improves the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering, the early identification and treatment of pain and other problems, physical, psychosocial and spiritual



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Palliative care

- ❖ **Provides relief from pain and other distressing symptoms**
- ❖ **Affirms life and regards dying as a normal process**
- ❖ **Intends neither to hasten or postpone death**



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- ❖ **Integrates the psychological and spiritual aspects of patient care**
- ❖ **Offers a support system to help patients live as actively as possible until death**
- ❖ **Offers a support system to help the family cope during the patient's illness and in their bereavement**



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- ❖ **Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated**

- ❖ **Will enhance the quality of life, and will also positively influence the course of illness**

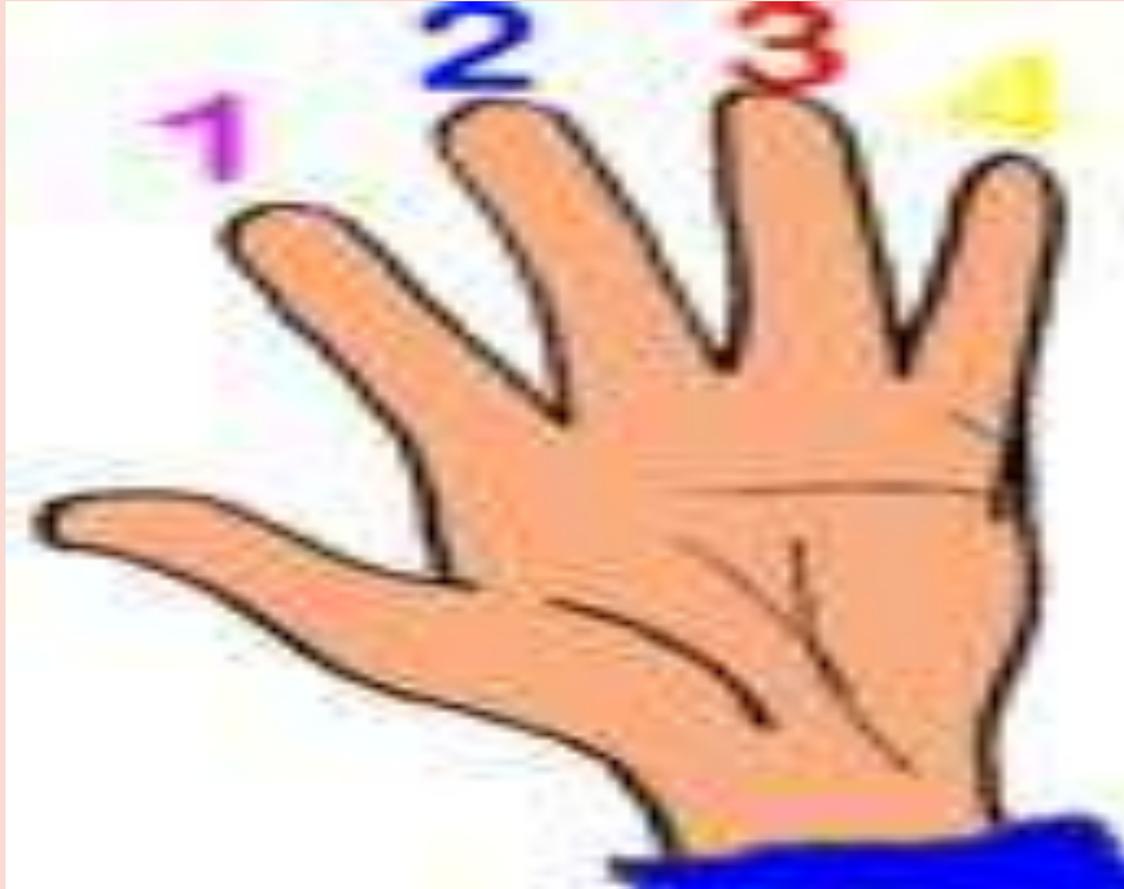


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- ❖ **Is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications**



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FOUR PHASES OF A DISEASE

- 1.Prevention of the disease (Education)
- 2.Prevention of advanced disease (Screening)
- 3.Prevention of death (Anti-cancer treatment)
- 4.Prevention of suffering (Palliative Care)



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WHAT DISEASES DOES PALLIATIVE MEDICINE COVER?

- ❖ **All diseases that are incurable and progressive and will result in the death of that patient in an indefinite time.**

Eg.: Cancer

AIDS

MND (ALS)

**End stage: Renal Failure
Cardiac failure
Emphysema
M.S.**



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WHO Definition of Palliative Care for Children

- ❖ Palliative care for children represents a special related field to adult palliative care. WHO's definition of palliative care for children and their families is as follows:



- ❖ Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- ❖ It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- ❖ Health providers must evaluate and alleviate a child's physical, psychological and social distress



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- ❖ Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- ❖ It can be provided in tertiary care facilities, in community health centres, and even in children's homes.



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The Key Principles of Palliative Care

- ❖ **Focus on quality of life**
- ❖ **Whole-person approach taking into account the person's past life experience and current situation**
- ❖ **Care which encompasses both the patient and those who matter to them**
- ❖ **Respect for patient autonomy and choice**
- ❖ **Emphasis on open and sensitive communication**

Interdisciplinary Team

- ❖ Trained and skilled in holistic care
- ❖ Doctors
- ❖ Nurses
- ❖ Social Workers
- ❖ Councillors
- ❖ Lay and professional volunteers
- ❖ Clergy



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“ For anyone privileged to look after patients, the duty to uphold, protect and restore the dignity of those who seek our care embraces the very essence of medicine.”

Harvey Chochinov



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Patient: JN

- ❖ Male
- ❖ single
- ❖ 48 years of age.



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Diagnosis:

- ❖ AIDS, Epileptic.
- ❖ Completed treatment of PTB
- ❖ Stroke- Right Hemiplegia



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- ❖ Request for admission by sister on home visit for pain and symptom control.
- ❖ No support system at home.
- ❖ No one to help patient.



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Social history:

- ❖ Had left home many years ago.
- ❖ Now returned home for care. Living with three nieces at the home. Two of the nieces are working in good jobs and one is a university student. Rest of family not interested in caring for him.
- ❖ He remains alone at home during the day. No family member is prepared to look after him physically due to poor family relations.



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On admission:

- ❖ Emaciated, paralysed right side, vague stare, unable to register questions and unable to give intelligent answers. Bedridden, not weight bearing.
- ❖ Requires assistance in feeding as he cannot feed himself.
- ❖ Pain on movement related to the stroke on the right side.
- ❖ Incontinent of urine and faeces.



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PALLIATIVE CARE BY ALL, FOR ALL



PALLIATIVE CARE BY ALL, FOR ALL

Management:

1. Drugs: Epilem 200mg BD
Carabermazine nocte
VIT BCo daily
Phenyton 100mg daily
Tramal 50 mg tds
2. Mouth Care
3. Bed baths / incontinent care
4. Assisted feeding
5. Social Worker intervention for family to care.



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- ❖ No family member is prepared to care for him.
- ❖ No one is prepared to partner him for ARV Clinic.
- ❖ Patient is receiving grant and is accommodated by the nieces who are not prepared to help with his nursing as well.
- ❖ Patient needs on going care.
- ❖ ? Nursing home- no funds.



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- ❖ Patient remains vague, confused and stares with no recognition.



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Dilemma:

1. Is it too late for ARV intervention as patient already has obvious CNS involvement.
2. Is stroke due to AIDS or CNS involvement.



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3. Who will take care
4. Family not prepared to do physical nursing.
5. Family is collecting grant money.
6. Who will partner him for ARV`s?



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5. How much active treatment is this patient to receive.
6. Poor prognosis
7. Where to from here?



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- ❖ Over the next week the patients condition started to deteriorate. He became more rigid, more vague. Condition is poorly.



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- ❖ His stay at the Hospice was extended as active medical management in the form of ARV`s would not be possible due to his poor medical condition.



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- ❖ Patient continued to deteriorate slowly. He became less communicable and eventually was unable to swallow and deteriorated.



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Patient MN

- ❖ Age: 29
- ❖ Gender: Male
- ❖ Marital status: Single
- ❖ Diagnosis: AIDS



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- ❖ On admission 15/05/09 patient referred by mother.
- ❖ CD4 count 2.
- ❖ Not on ARV`s due to sclerosing cholangitis.
- ❖ Has been admitted to Greys Hospital in Pietermaritzburg and has had a full work up done and also fully investigated at KEH.
- ❖ Not suitable for ARV`s.



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On examination:

- ❖ confused,
- ❖ oral thrush,
- ❖ bed ridden
- ❖ diarrhoea.



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Social History:

- ❖ Living with mother in servant's quarters.
- ❖ Mother has not informed employer that her son is living with her.
- ❖ Gloves and food parcels left with the family.
- ❖ July 2009 condition deteriorating and getting weaker now incontinent of urine.
- ❖ Unable to sit up and needs help bathing.
- ❖ Able to eat 3 meals a day.



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- ❖ Admitted to the Hospice on 06/08/09 for symptom management.
- ❖ On examination patient has sores on his body, weak, jaundiced, distended abdomen, and unable to bear weight. Incontinent of urine.
- ❖ Mother unable to care for him as he lives secretly with the mother.



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- ❖ Medical Treatment: Diflucan 200mg daily, B Co 1 daily
- ❖ Social workers counseling patient and mother and arranging placement.
- ❖ Supportive care continued until patient was put into placement.



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- ❖ Hospice paid for a chest x-ray to exclude TB and patient was discharged on the 17/08/09 into placement.



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- ❖ Mother was unhappy with the placement and took him back home.
- ❖ 24/08/09 patient was re-admitted to the Highway Hospice for terminal care.



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- ❖ AIDS is a complex disease with good available treatment and management.
- ❖ Disease cannot be treated in isolation
- ❖ Holistic care is very important
- ❖ Good prognostication
- ❖ Good skills to address end of life issues
- ❖ Realistic expectation of disease response.



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- ❖ HIV+ and 17 years on ARV
- ❖ Cancer of the vulva
- ❖ Oncologist, HIV Clinician, Palliative Care



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Conclusion

“For anyone privileged to look after patients, the duty to uphold, protect and restore the dignity of those who seek our care embraces the very essence of medicine.”

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