



Introduction

- **“the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families”**

WHO

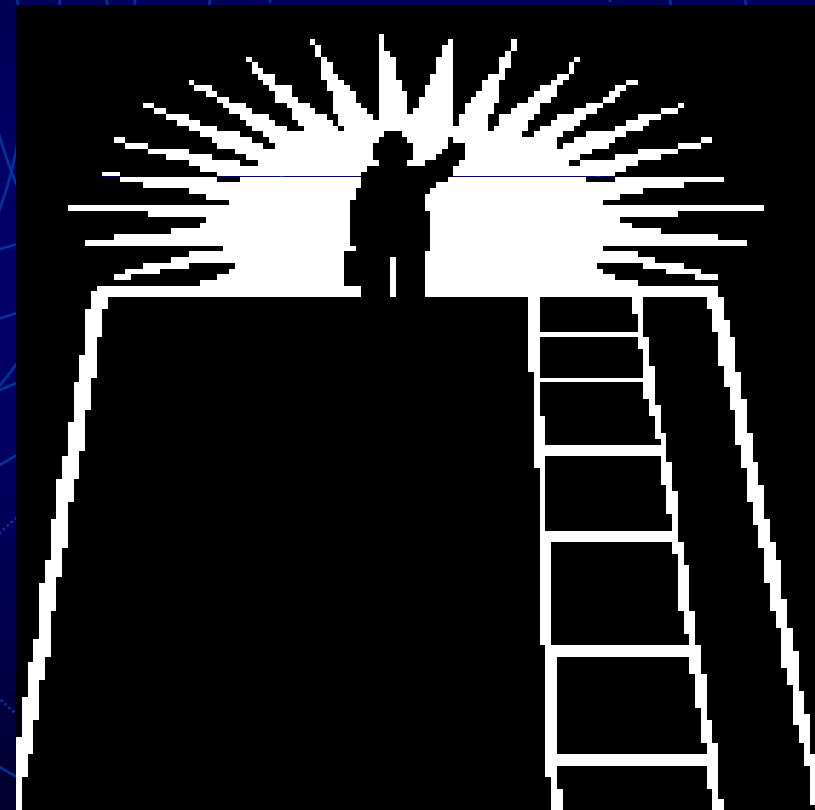


Introduction

- **Multidisciplinary.**
- **Doctors get stuck on the prescribing of drugs which is only a small part.**

Principles

- **Analgesic ladder**
- **Not Just MST !**
- **Total pain relief
needs attention to
all aspects of pain**





Physical Pain

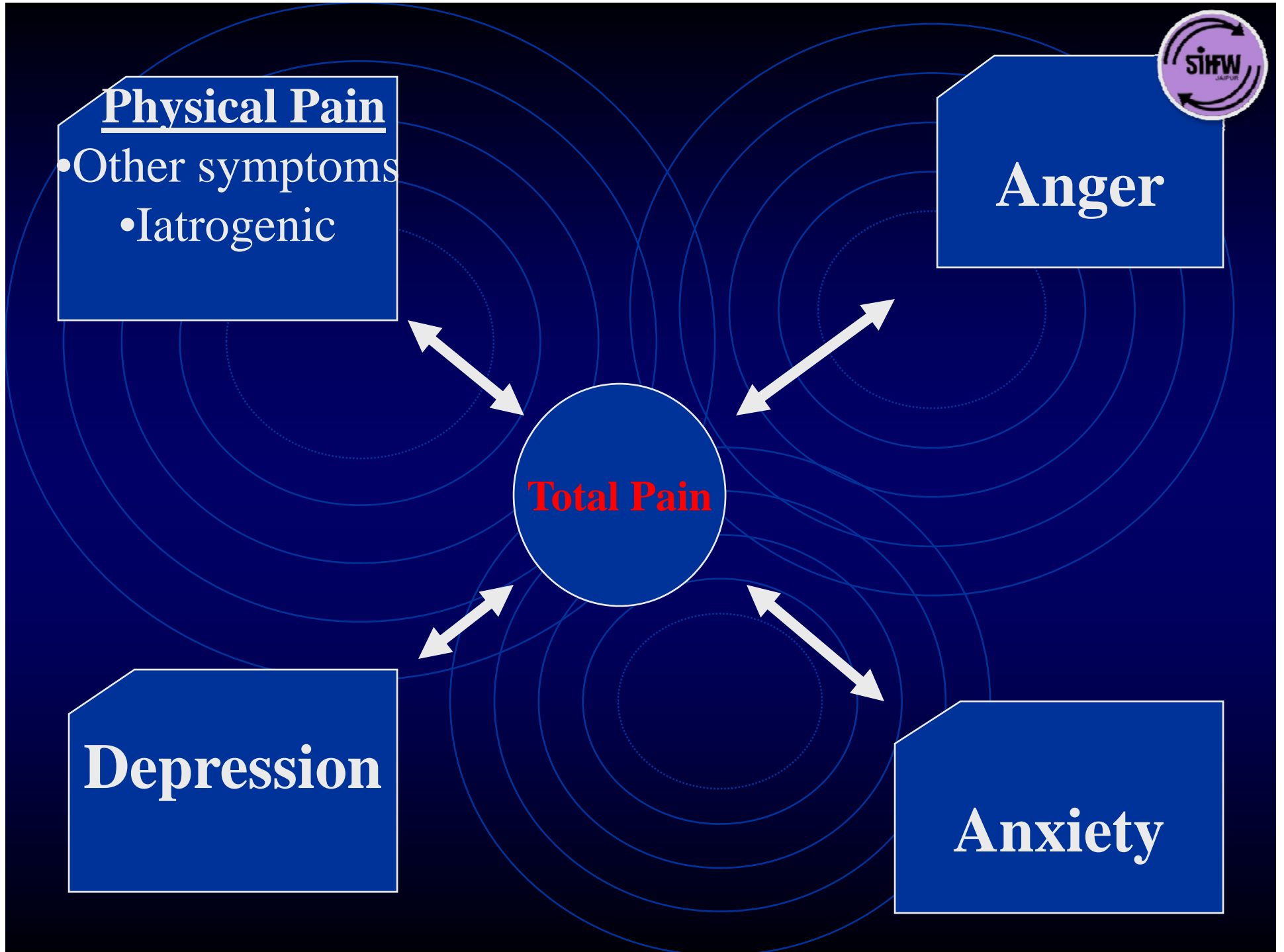
- Other symptoms
- Iatrogenic

Anger

Total Pain

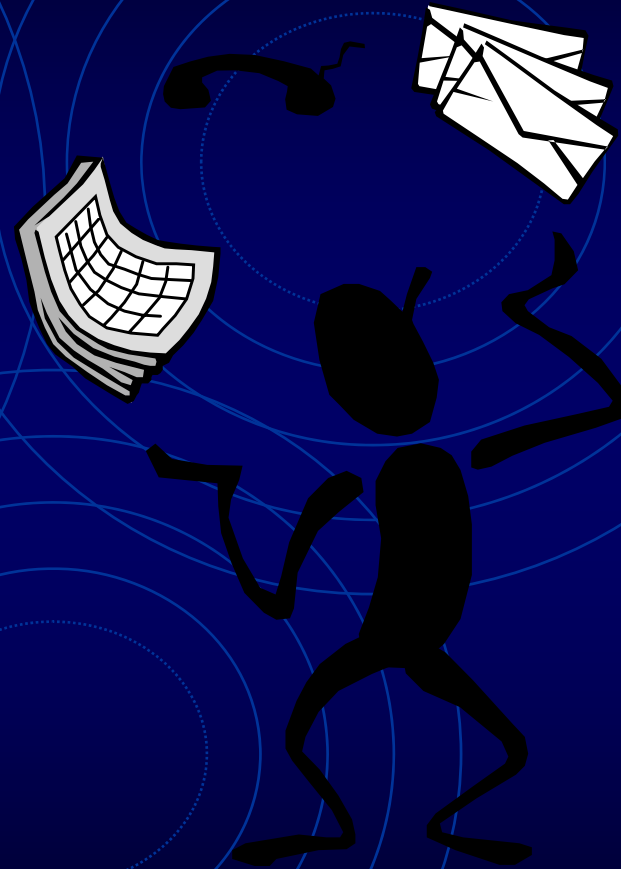
Depression

Anxiety



Orchestration

- **The job par excellence of the GP.**
- **Team building**
- **Patients and carers need consistency in advice etc**

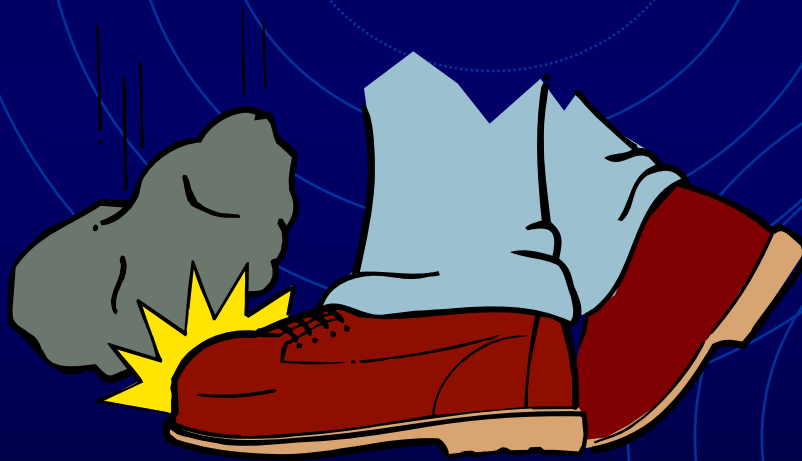


Skin Etc

- **Mouth care**
- **Pressure sores**
- **Malignant ulcers**
- **Lymphoedema**



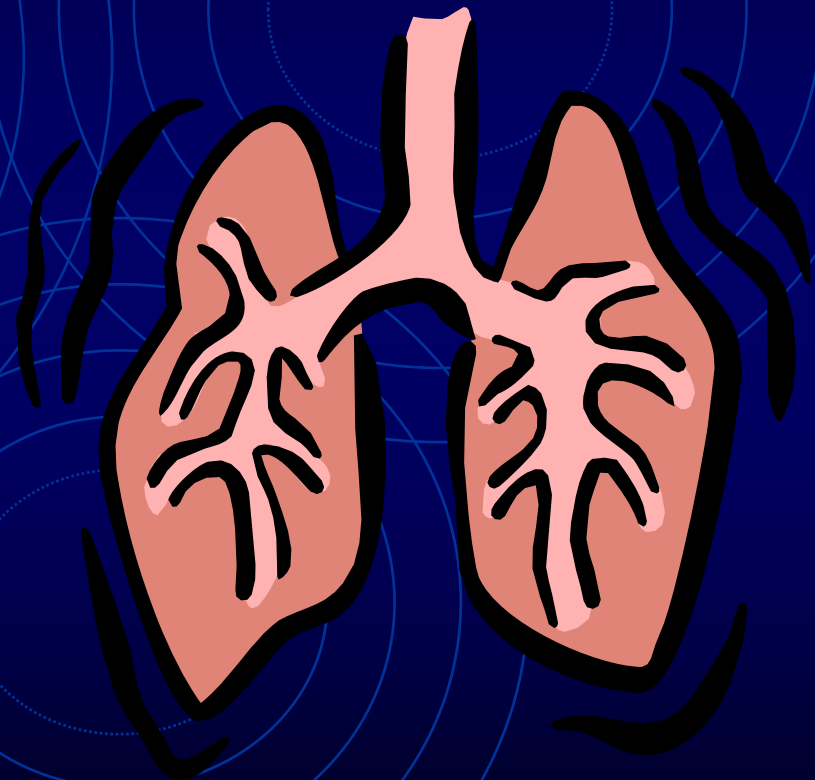
Pain Problems



- **Route of administration**
- **Non drug methods**
- **Neuropathic pain**
- **Bone pain**
- **Incident pain**
- **Visceral pain**
- **Anaesthetic techniques**

Respiratory Symptoms

- **Breathlessness**
- **Cough**
- **Haemoptysis**
- **Stridor**
- **Pleural pain**



GI Problems

- **Nausea and vomiting**
- **Obstruction**
- **Constipation**
- **Anorexia**
- **Cachexia**
- **Diarrhoea**



Emergencies



- **Some acute events should be treated as emergencies if a favourable outcome can be achieved.**
- **Hypercalcaemia**
- **SVC obstruction**
- **Spinal cord compression.**



Emergencies

- **Fractures**
- **Careers becoming ill**
- **Breakthrough symptoms**
- **Crises of confidence**

Mental Health

- **Psychological adjustment reactions are usual.**
- **10-20% develop formal psychiatric disorders which should be treated.**
- **Not just “something to be expected” and ignored.**
- **Now the most under treated and recognised area of palliative care.**



Non Drug Therapies Should Not Be Forgotten.



- **The GP as a caring professional is mightier than the FP10.**
- **Lift the heart !**
- **Remember others who may help e.g. the clergy**
- **Consistent care**
- **Remember treatable causes of confusion**



Not Cancer !

- **MS**
- **Motor neurone disease**
- **COPD**
- **CJD**
- **Heart failure**
- **Liver failure**

Etc etc

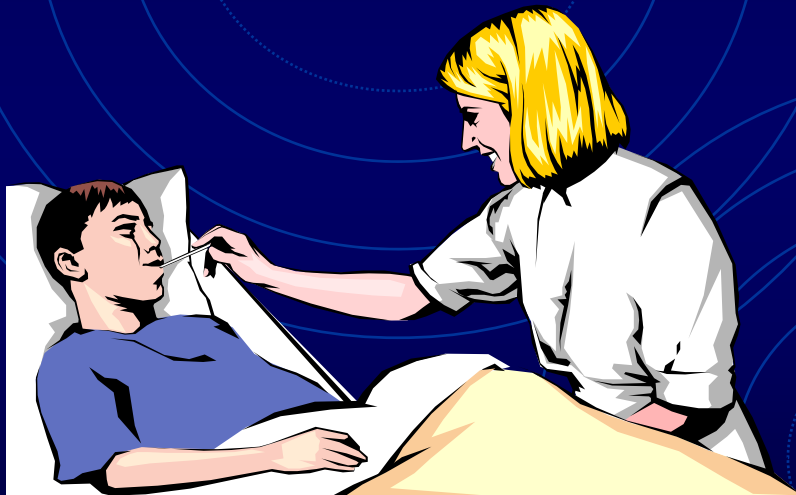


Special Groups

- **Children**
- **HIV / AIDS**
- **Ethnic groups**



Carers



- **Family and friends**
- **Must remember their needs**



Needs of Carers

Information and education about:

- **The patient's prognosis.**
- **Causes, importance and management of symptoms.**
- **How to care for the patient.**
- **How the patient might die.**
- **Sudden changes in condition and what to do**
- **What services are available.**



Needs of Carers

Support during the illness

- **Practical and domestic.**
- **Psychological.**
- **Financial.**
- **Spiritual.**

Bereavement

- **See latter.**



Needs of Carers

Sources of support.

- Symptom control

GP, DN, Nurse specialists eg Macmillan,
Palliative care doctors.

- Nursing

Community nurses, private nurses, Marie
Curie.

- Night sitting

Marie Curie, DN services



Needs of Carers

- Respite care

**Community Hospitals, Nursing homes,
Hospices.**

- Domestic support

Social services.

- Information

**GPs, DN, Macmillan, Voluntary
organisations ie BACUP..**



Needs of Carers

- Psychological support

Bereavement counsellors, DN, Macmillan.

- Aids and appliances

OT, PT, DN and social services.

- Financial assistance

Social services.

Communication

- **Absolutely vital.**
- **Breaking bad news**
- **Denial**
- **Collusion**
- **Difficult questions**
- **Emotional reactions**





Elicit Person's understanding

Does the person know or suspect the truth?

No

Yes

"Fire warning shot"

Break news at person's pace in manageable chunks

Explore level of knowledge

Confirm news at person's pace

Acknowledge immediate reactions

Allow time for initial shock

Deal with reactions and questions

Offer support as needed

Denial

- **May be strong coping mechanism**
- **Relatives may encourage**
- **May be total – rare**
- **May be ambivalent**
- **Level may change over time**





Dealing With Collusion

- **Explore reasons for collusion.**
- **Check cost to colluder of keeping secret.**
- **Negotiate access to patient to check their understanding.**
- **Promise not to give unwanted information.**
- **Arrange to talk again and raise possibility of seeing couple together if both aware of reality.**



Dealing With Difficult Questions

- **Check reason for question e.g. “why do you ask that now?”**
- **Show interest in others ideas e.g. “I wonder how it looks to you?”**
- **Confirm or elaborate e.g. “you are probably right” .**
- **Be prepared to admit you don’t know.**
- **Empathise e.g. “yes, it must seem unfair”.**



ANGER

Effective

Acknowledge
anger

Identify focus

Legitimise

Encourage expression



Anger is
diffused

Ineffective

Dismiss anger

Refute focus

Defend actions of
colleagues



Anger
increases

Last Days

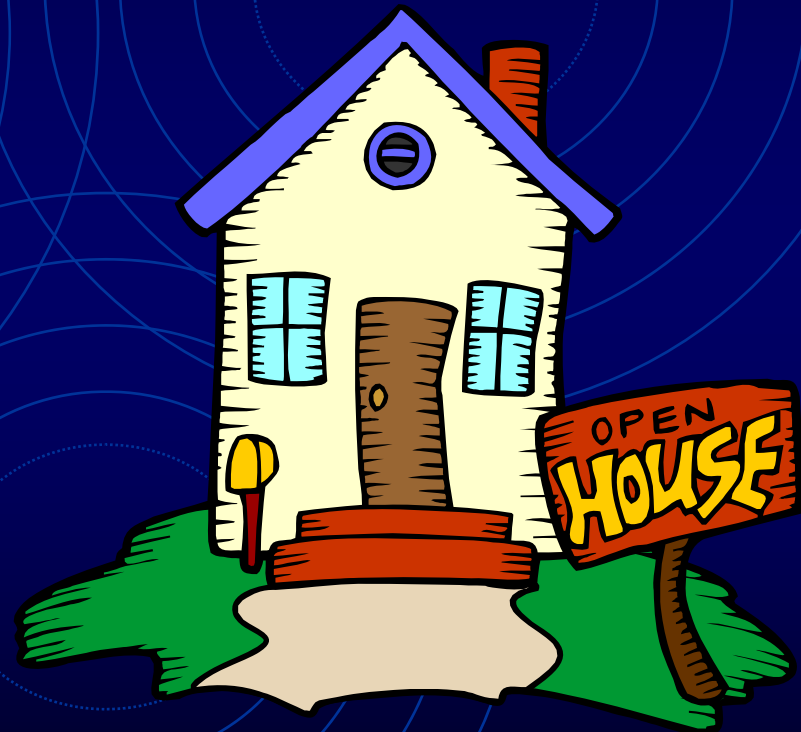
- **Final deterioration can be rapid and unpredictable.**
- **Symptom control and family support take priority.**
- **Emotional levels and stress can be very high.**
- **Review of drugs in terms of need and route of administration.**
- **Drugs should be available for immediate administration by nurses.**



Care at Home

- **Coordination**
- **Coordination**
- **Coordination!**

- **Communication**
- **Teamwork**



Bereavement



- **A whole topic in self !**
- **Remember it !**
- **Don't stop when the person dies !**
- **Stages of grief**
- **What helps?**
- **Support groups**

Is there a problem

- ‘Dying’ is as old as humanity – so why is there a problem?
- In the past the dying person knew the right thing to do.
- Ars Moriendi





Is there a problem?

- The contemporary world:
- None of the certainties of a shared faith
- Many new uncertainties
- Changed expectations
- The cult of the 'self'
- Underpinned by 'legal rights' mentality 'It's my right'
- The promises of medical biotechnologies
- What money *can* buy

Paternalism



Paternalism



Tender, loving, care!



- ‘You will have a bath Mr Jensen, it will make you feel much better’

From: Every Woman's Encyclopaedia.



Autonomy

- Ancient Greek politics *auto* (self) *nomos* (governing)
- Kant the autonomous self is capable of thinking and reasoning
- Anglo-American/ Western Liberal – principle of respect for autonomy

Autonomy



- The individual
- Sovereign self with positive and negative rights
- free from interference
- Right to determine one's own life



*Just let me make
my own decisions*



*Mrs Andersen know her
own mind.*



Let me make my own decisions

Sedate
me



Don't tell
my family
I am dying

Send me
home to
die

Resuscitate
me

Feed me
until the
end



I want
euthanasia

I don't want
morphine





A common dilemma

- ‘Don’t tell him he is dying’!
- Sitting on the arm of his chair she observed my every move, anticipated every question in the fear that I might let something slip.
- And all the time in her eyes was written ‘I know you are dying but we must never talk about it’ and all the time written into his face was the thought ‘I know I am dying but she must never know’ ...



Autonomy and truth

- Truth is not merely a matter of words and we are likely to find the particular truth that is fitted to our patient's need only in some kind of relationship with him.
(Saunders 1984:4)



What is Palliative Care?

- Medical care that focuses on alleviating the intensity of symptoms of disease.
- Palliative care focuses on reducing the prominence and severity of symptoms.



What is Palliative Care?

- The World Health Organization describes palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and management of pain and other problems, physical, psychosocial and spiritual."



WHO Definition of Palliative Care



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;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients as actively as possible until death;



WHO Definition of Palliative Care



(cont.)

- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.





What is the goal of Palliative Care?

- The goal is to improve the quality of life for individuals who are suffering from severe diseases.
- Palliative care offers a diverse array of assistance and care to the patient.



The History of Palliative Care

- Started as a hospice movement in the 19th century, religious orders created hospices that provided care for the sick and dying in London and Ireland.
- In recent years, Palliative care has become a large movement, affecting much of the population.
- Began as a volunteer-led movement in the United states and has developed into a vital part of the health care system.



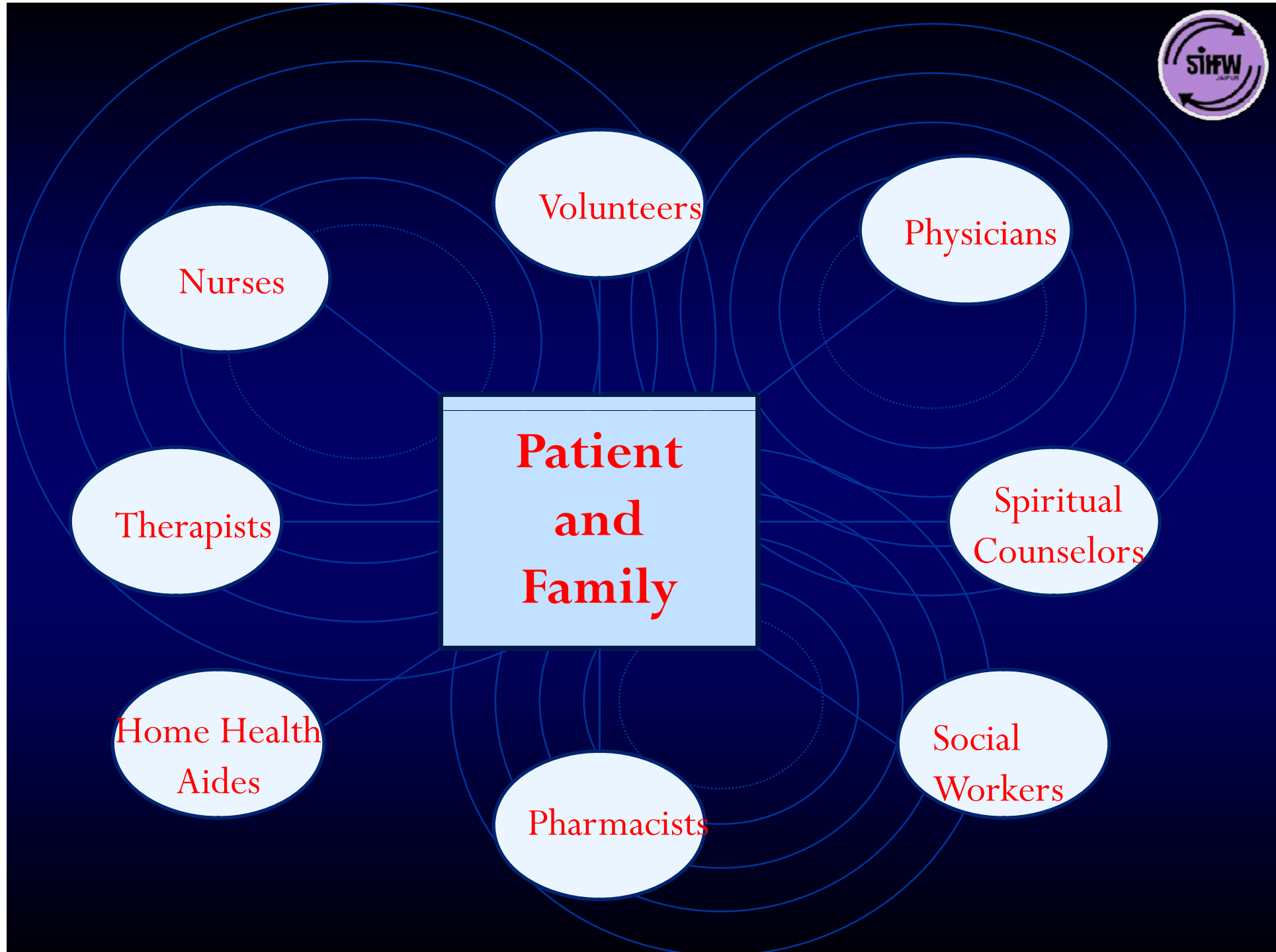
Who receives Palliative Care?

- Individuals struggling with various diseases
- Individuals with chronic diseases such as cancer, cardiac disease, kidney failure, Alzheimer's, HIV/AIDS and Amyotrophic Lateral Sclerosis (ALS)



Who Provides Palliative Care?

- Usually provided by a team of individuals
- Interdisciplinary group of professionals
- Team includes experts in multiple fields:
 - Doctors
 - Nurses
 - social workers
 - massage therapists
 - Pharmacists
 - Nutritionists



Nurses

Volunteers

Physicians

Patient
and
Family

Therapists

Spiritual
Counselors

Home Health
Aides

Social
Workers

Pharmacists

Approaches to Palliative Care

- Not a “one size fits all approach”
- Care is tailored to help the specific needs of the patient
- Since palliative care is utilized to help with various diseases, the care provided must fit the sy

Palliative Care

Image courtesy of uwhealth.org

Palliative Care Patient Support Services



- Three categories of support:
 1. Pain management is vital for comfort and to reduce patients' distress. Health care professionals and families can collaborate to identify the sources of pain and relieve them with drugs and other forms of therapy.

Palliative Care Patient Support Services



2. Symptom management involves treating symptoms other than pain such as nausea, weakness, bowel and bladder problems, mental confusion, fatigue, and difficulty breathing



Palliative Care Patient Support Services

3. Emotional and spiritual support is important for both the patient and family in dealing with the emotional demands of critical illness.



What does Palliative Care Provide to the Patient?

- Helps patients gain the strength and peace of mind to carry on with daily life
- Aid the ability to tolerate medical treatments
- Helps patients to better understand their choices for care



What Does Palliative Care Provide for the Patient's Family?

- Helps families understand the choices available for care
- Improves everyday life and reduces the concern of loved ones
- Allows for valuable time and support system



Image courtesy of mdanderson.org



Approaches to Palliative Care

A palliative care team delivers many forms of help to a patient suffering from a severe illness, including :

- Close communication with doctors
- Expert management of pain and other symptoms
- Help navigating the healthcare system
- Guidance with difficult and complex treatment choices
- Emotional and spiritual support for the patient and their family



Palliative Care Is Effective

- Successful palliative care teams require nurturing individuals who are willing to collaborate with one another.
- Researchers have studied the positive effects palliative care has on patients. Recent studies show that patients who receive palliative care report improvement in:
 - Pain and other distressing symptoms, such as nausea or shortness of breath
 - Communication with their doctors and family members
 - Emotional and psychological state



Settings for Palliative Care

- Outpatient practice
- Hospital Inpatient
 - Unit based
 - Consultation Team
- Home care
- Nursing Home
- Hospice