



Psychosocial and Spiritual Support in Palliative Care For FLW





LEARNING OBJECTIVES

- List Do's & Don't s when addressing the psychosocial needs of the patient/ family.
- Describe the protocol for communicating effectively with a distressed individual.
- Understand the psychosocial and spiritual experience and needs of patients and families as the illness progresses and after bereavement
- Understand principles of empathetic communication and learn skill of the same
- Understand the role of difficult emotions like anger and fear while dealing with emotional issues



TOTAL PAIN- TOTAL CARE

Physical Pain

Mobility issues
Bowel problems
Inability to sleep

Psycho-social

Concerns about children/parents
Isolation from neighbours
No support from relatives

TOTAL PAIN

Socio-economic

Cost of treatment
Loss of job due to illness
Wife uneducated and cannot work
Children's education

Spiritual

Loss of hope
Despair
Loss of connection



LET'S FIND OUT THE ANSWER TOGETHER

During your home visit you came across a bedridden man with advanced illness from a low socioeconomic background. Before you start anything, he asked you:

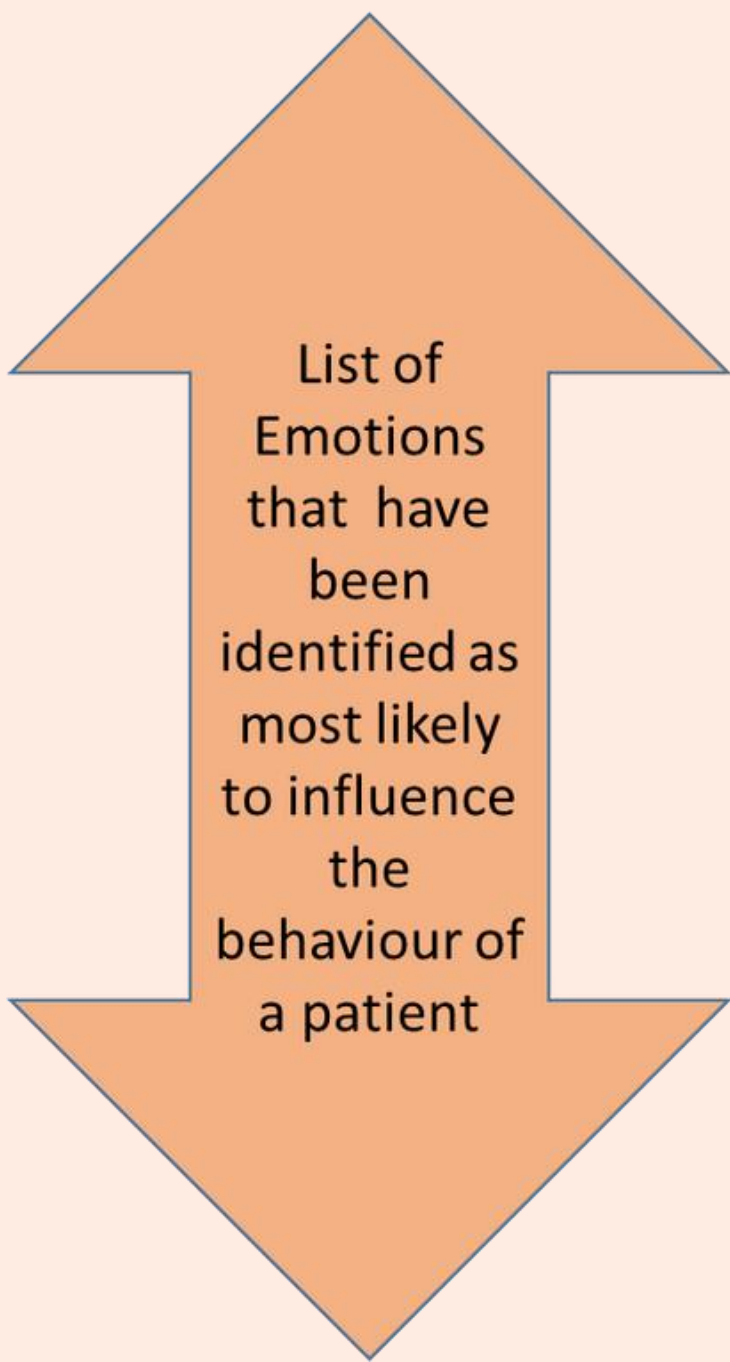
“I don't want to live like a burden”

“How much time do I have?”

“When will I die?”

THE POSSIBLE PSYCHOLOGICAL IMPACT OF ILLNESS

- Anger (*Why me?*)
- Fear (*What will happen to me?*)
- Loss (*I have lost everything that gave my life value*)
- Guilt/Blame (*I should have gone earlier to the doctor/I did not have the money to see a proper doctor*)
- Shame (*How will people now treat me and my family?*)
- Grief/Despair (*This will only get worse and end in suffering and death*)
- Hope (*I shall remain pain free and continue to function independently*)



List of
Emotions
that have
been
identified as
most likely
to influence
the
behaviour of
a patient

WHAT IS THE SITUATION? WHERE DO WE BEGIN?

PATIENT'S REALITY

- Increasing dependence on others
- Loss of confidence, control and autonomy
- Feelings of guilt; of becoming a burden
- Fear of suffering and death
- Loss of meaning or sense of connection

PATIENT'S NEED

- To participate in decision making about own illness
- To be treated with respect
- To be heard and to ventilate feelings
- To continue to live with dignity
- To resolve conflicts
- To receive peace and forgiveness
- To get permission to die



FAMILY'S REALITY

- Exhaustion
- Feel alone
- Anxious and/or depressed
- Uncertain about future course of action
- Lack of finances/resources
- Unable to see or maintain hope

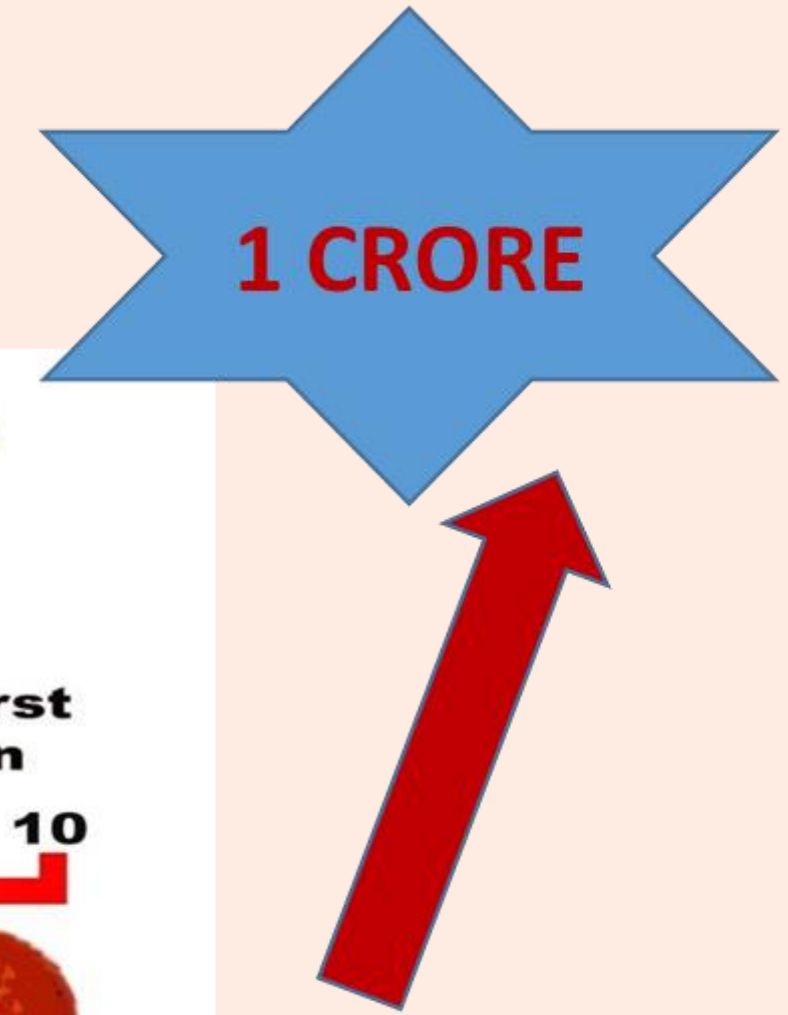


FAMILY'S NEED

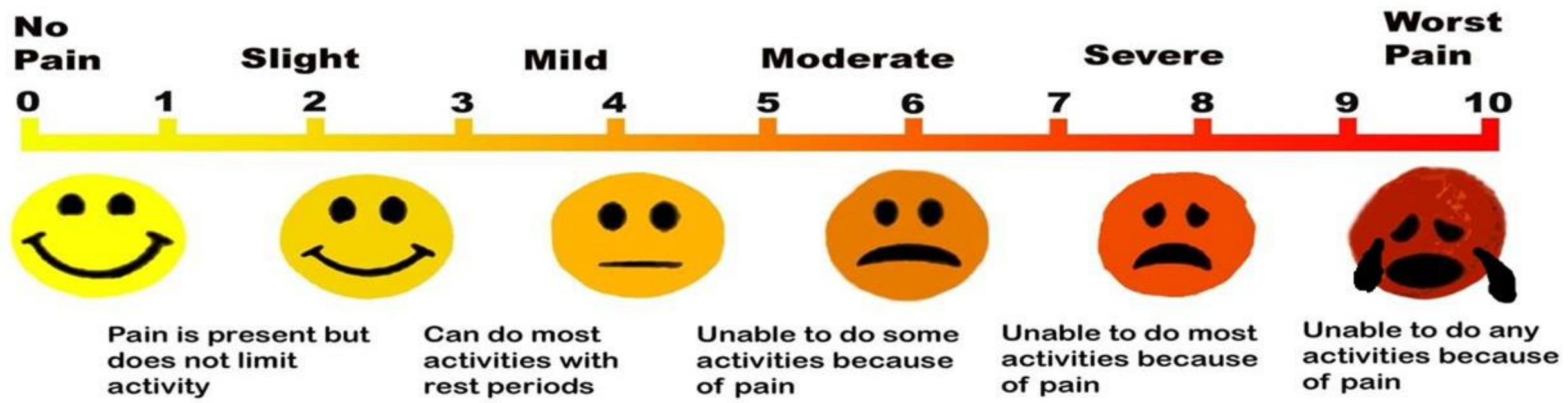
- To be able to **express feelings** openly
- To **ask questions** and receive honest answers
- To get **help** to resolve family conflicts, etc.
- To get **reassurance and information**
- To receive affordable medical, nursing and emotional **support**



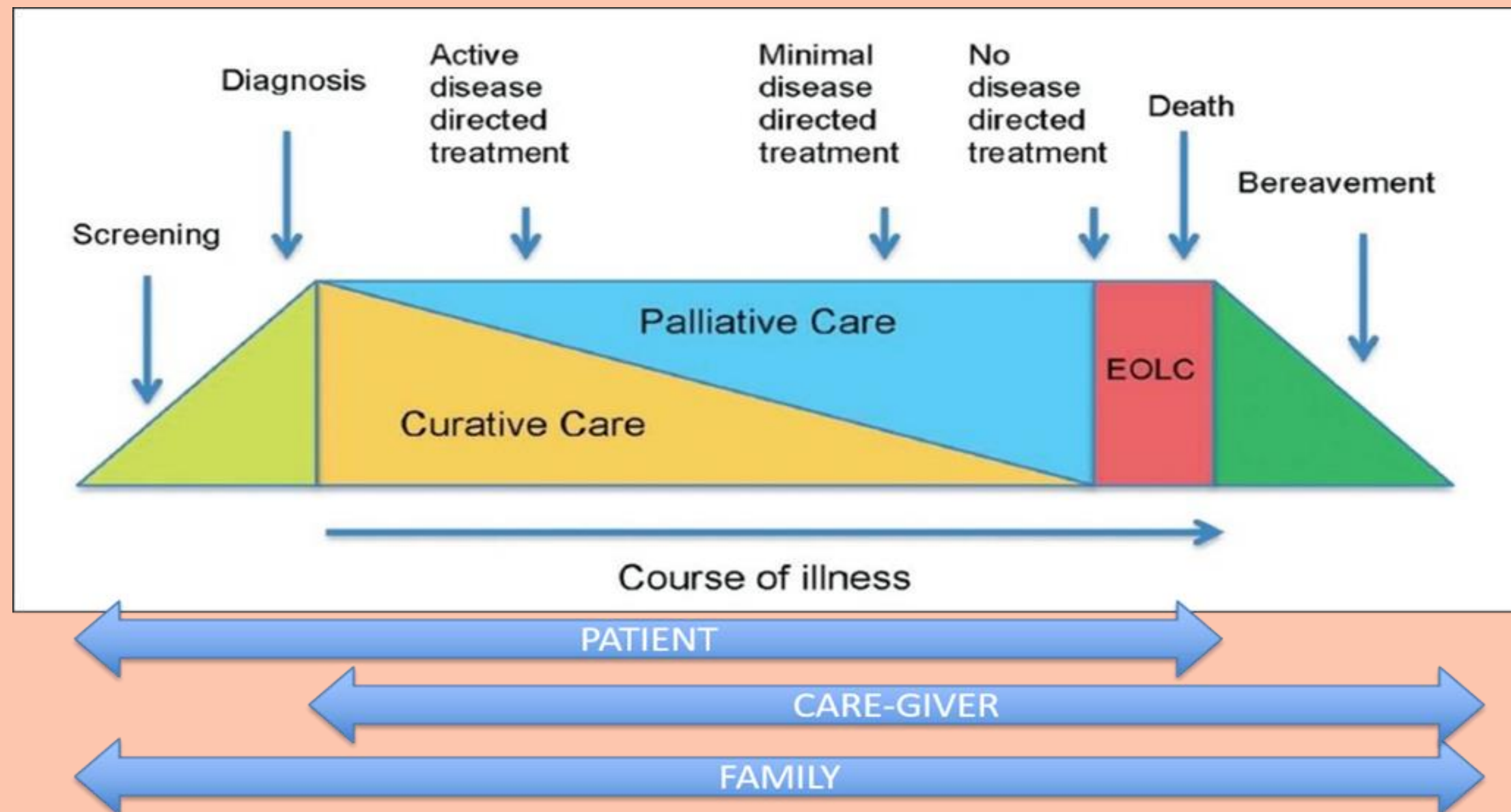
UNIVERSAL PAIN SCALE



How is your Pain Today?



PSYCHOLOGICAL AND SPIRITUAL NEEDS WILL DIFFER ALONG THE COURSE OF PALLIATIVE CARE





PALLIATIVE
PERSON FEELS

ANGER

FEAR

GUILT BLAME

LOSS

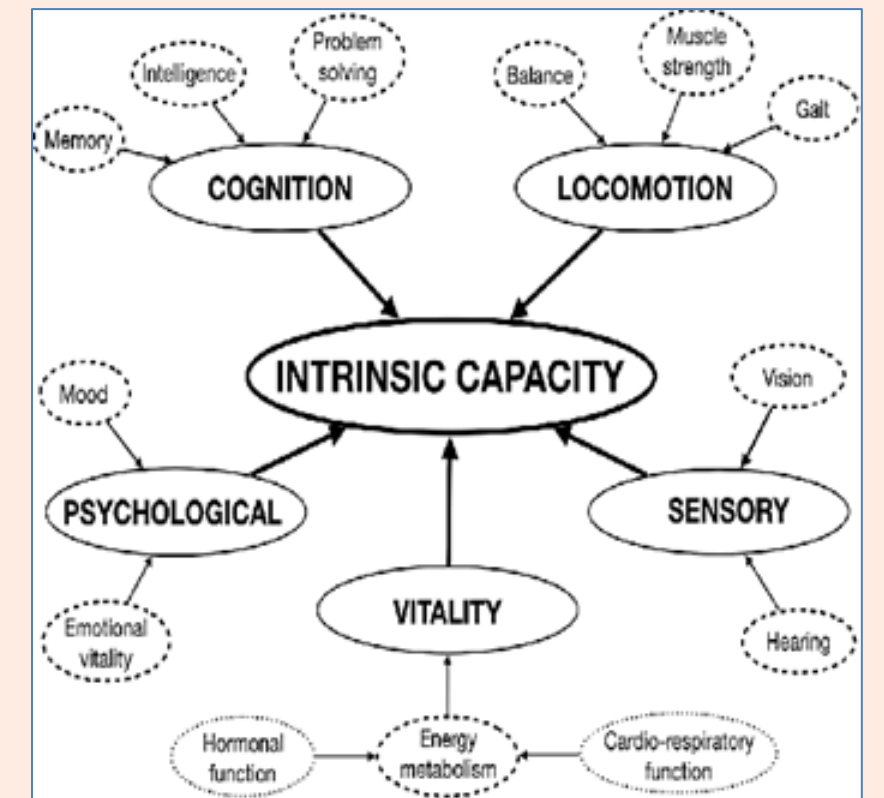
ILLNESS

WHAT CAN
WE DO?

? INTRINSIC
CAPACITY

? FUNCTIONAL
ABILITY

HEALTH AND WELLNESS





ASSESSING PSYCHOSOCIAL AND SPIRITUAL SUFFERING



Purposeful Observations

Purposeful Conversations

**EMPATHETIC
COMMUNICATION**

Some ????????

- Who to communicate with?
- What to communicate?
- How to communicate?
- When to communicate?

TIP:

Focus on the Patient and the decision-maker. Remember that the main caregiver may not be the decision-maker.
Don't forget the children.

No easy answers.
Let us learn some thumb rules

COMMUNICATION DOS' & DON'T

Do NOT

Avoid eye contact

Rush in to tell the truth

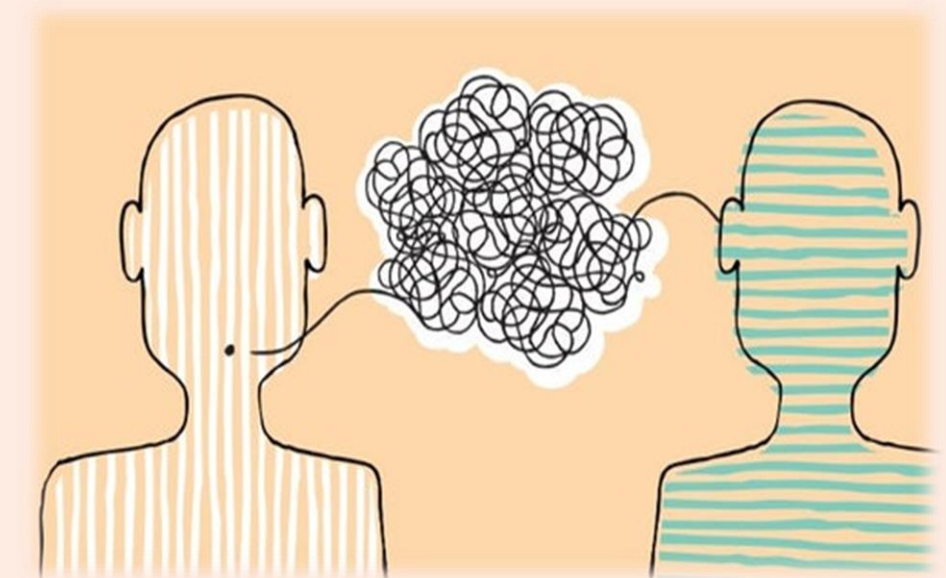
Answer direct questions such as,
“When will I die?” or “How long do I have?”

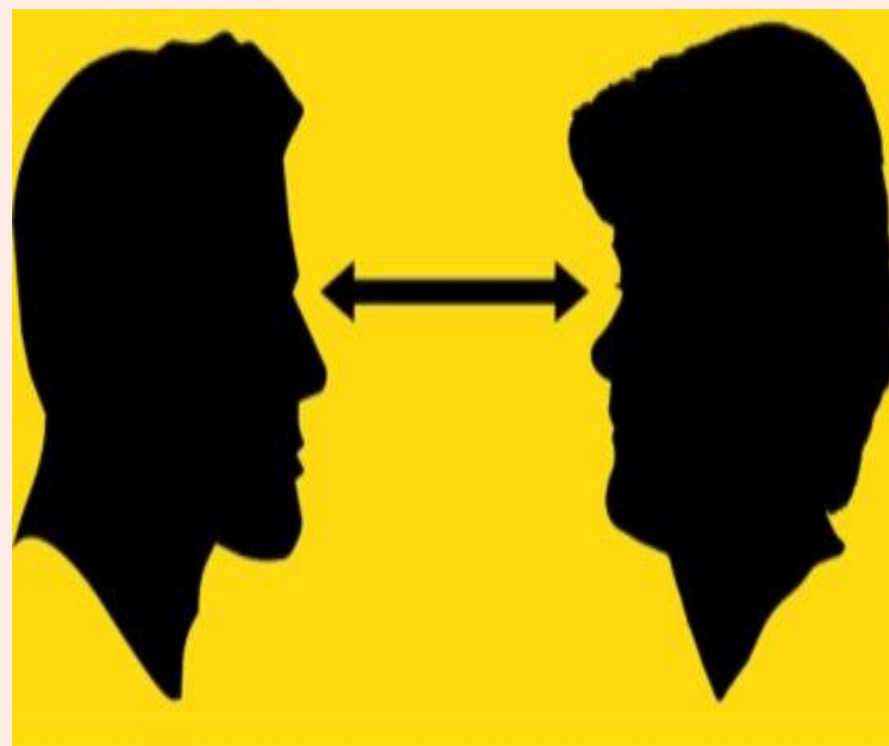
Ask leading questions
“Your pain is better now, isn't it?”

Minimize / compare patient's problems
“Don't get so worried over such small problem.”
“There are so many people who are facing much bigger problems.”

Give false hope
“Don't worry, we are with you, we will take care of all your problems. Everything will be alright.”

Assume
“Don't worry, even if your cancer is advanced, we have all the medicines to keep you comfortable.”





Do

Make eye contact

Gauge readiness of patient and family to accept the truth. Give bad news in small doses.

Ask a counter question like, “Why do you ask?” or “Is there anything in particular that you want to do?”

Ask open-ended questions like “How are you feeling?” or “What is your concern?”

Acknowledge/ normalize patient’s emotional experience
“Anybody in your position would perhaps feel this way”
“Considering what you’re going through, it’s normal to feel this way.”

Give realistic hope
“Your disease may be progressive, but I’ll do my best to keep you comfortable as long as its needed.”

Ask what their concerns are
“What is your biggest concern right now?” (The answer could be “How will my children eat tonight?”)



LISTENING

R RELAXED

O OPEN POSTURE (*do not fold your arms*)

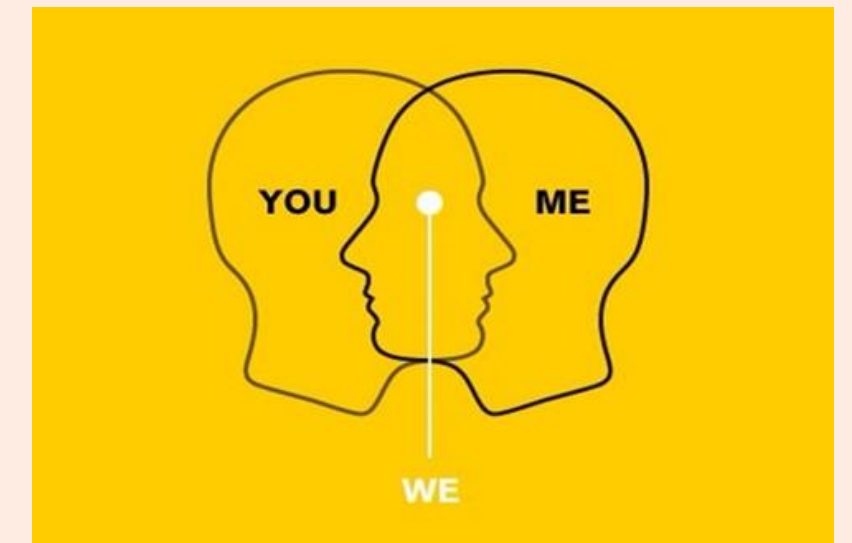
L LEAN FORWARD

E KEEP EYE CONTACT

S SAY AHA, NOD,
REPEAT WHAT THEY SAY

BENEFITS OF EMPATHETIC LISTENING

1. It removes uncertainty; patient copes better
2. Patient and family can make informed choices
3. Prevents unrealistic hope and loss of scarce resources
4. Gives opportunity to express emotions
5. Leads to better compliance as patient and family move from denial to acceptance



DEALING WITH EMOTIONAL ISSUES

Be ready

- Sometimes unfocused anger or fear converted into anger may be directed at you. Be **calm**.

Listening is key

- The best way to deal with this is to **listen without interruption**.

Venting is good

- By the time they finish, they will be relieved of their anger and grateful to you for giving them the opportunity to express themselves.

Why not talking

- There are patients who become uncommunicative and withdraw. Do not assume that they do not want to talk. Consider why they have withdrawn

Support caregiver

- Very often after the death of a patient caregivers feel guilty. They feel that they did not do enough: “If only I had more money?” “If only I could have taken him or her to a particular hospital?” etc. **The best way to deal with this is to ask the caregiver to make a list of the things they did for the patient.** This will help them realize that they have done a great deal and make them less guilty.

Realistic hope not false hope

- Never forget hope; it always has a place no matter what the prognosis. Our task is to foster it at all stages but **not to give false hope**

DEALING WITH SPIRITUAL ISSUES

ISSUES	TIPS/ SOLUTIONS
Spiritual issues often stem from a sense of loss of meaning, connection and hope.	Not only religious. Ask questions that will make them reflect on and remember where they still find meaning, connection and hope.
Patients will often ask “How much time do I have?” “When will I die?” “What will happen to me after I die”	Explore fears. Respond with empathy. Avoid personal views and beliefs
Patients often confide that they wish to go in peace	Often what they are asking for is help to resolve some unfinished business.





DEALING WITH SPIRITUAL ISSUES

ISSUES	TIPS/ SOLUTIONS
There are patients who talk about ending their lives	This is a cry for help that can be met with the right medical, nursing, psychosocial and spiritual response. Remain vigilant for suicide risk, depression, mental health issues. Do not dismiss or downplay their distress.
There may be caregivers who are finding it difficult to cope with loss and grief after the death of a loved one, worsened by poverty etc.	We should be able to recognise grief that refuses to resolve.
Caregivers may also have their own set of spiritual questions at this stage: “How is my loved one?” “Where is he or she now?” “How could God allow this?” ‘Will I see them again when I die?’	It is not the answers we give that matter as much as how comfortable people are to discuss their deepest feelings with us and thereby find inner peace.



SPIRITUAL WELL-BEING

- Interconnectedness with the world
- Meaning / Purpose
- Strength and Comfort
- Hope

Remember:
Spirituality is often related to belief in God or religion.
BUT
Not necessarily related to God or religion.

Before tackling spiritual issues:

- Ensure physical symptoms are controlled
- Convey that you care
- Establish rapport
- Concurrently handle psychosocial issues

CASE STUDY – ACTIVITY 3

During the visit by HWC team, it was observed that Ms. Savitri 52 year old lady, living with her unmarried 26 year daughter who is breadwinner for the family, diagnosed with breast cancer (stage IV) was very anxious and distressed. She is undergoing chemo/radiotherapy on monthly basis. She was crying repeatedly while talking. She asked the ASHA/ANM why she developed this condition, what evil she has done in her life, why only she has to suffer this much. She also expressed worries about her daughter.

- **How would you plan a communication session with Savitri?**
- **How would you like to include Savitri's children in the entire discussion, if yes, how?**

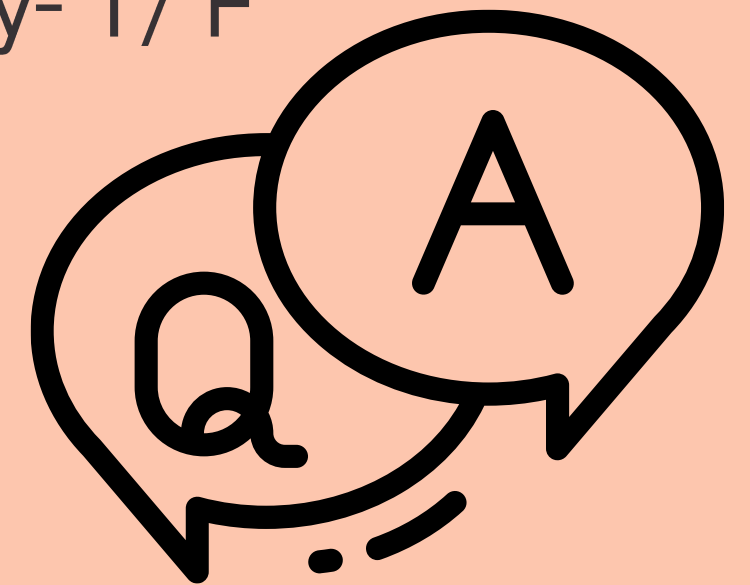
SUMMARY NOTES

- Palliative Care is incomplete unless we address the psychosocial and spiritual issues of patients and their caregivers.
- Empathic listening is vital, and is about:
 1. ROLES
 2. Relationship-building
 3. Observation of the patient and family
 4. Identification of the psychosocial and spiritual issues through effective communication
 5. Formulation of goals
 6. Assessment and evaluation
 7. Regular follow-ups
- Referral should be done wherever needed to HWC.
- Should be conscious while communicating and should know our limit (never to give false hope)



Q & A TIME

1. Spiritual issues are only related to religion- T/ F
2. Statement like “Don’t worry you will not die for next 1 year” should be the starting statement during communication- T/ F
3. Sympathy needs more level of understanding than empathy- T/ F
4. Total pain consist of _____, _____, _____, _____
5. “I feel your suffering” is Empathy- T/ F
6. “ You were saying that you feel lonely, is that right, Raju?” This is empathetic listening T/F



Q & A TIME

1. Spiritual issues are only related to religion- T/ **F**

2. Statement like “Don’t worry you will not die for next 1 year” should be the starting statement during communication- T/ **F**

3. Sympathy needs more level of understanding than empathy- T/ **F**

4. Total pain consists of **Physical, Psycho-social, Financial and Spiritual**

5. “I feel your suffering” is Empathy- **T**/ F

6. “ You were saying that you feel lonely, is that right, Raju?” This is empathetic listening **T**/F



Thank You

