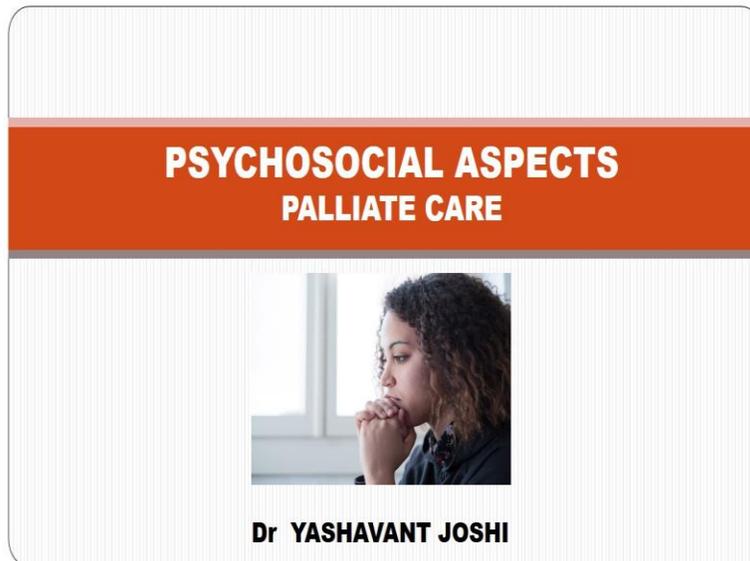


**Basic Certificate in Palliative Care**  
**Dr. Geeta Joshi**  
**Dr. Piyush Gupta**  
**Dr. Col. Yashavant Joshi**  
**International Institute of Distance Learning**  
**Indian Institute of Technology, Kanpur**

**Week-03**  
**Lecture 02: Psychological Aspects in PC**

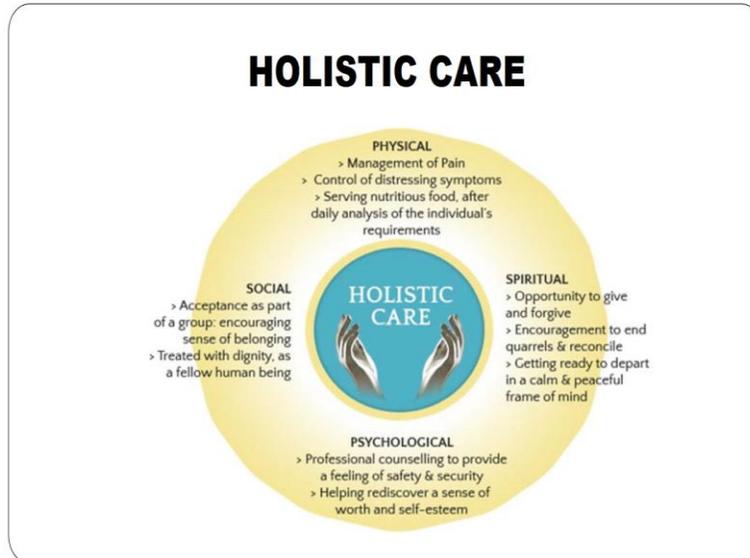
Week number 3, lecture number 2. Hello, Hello friends. So, the third week of our course, basic certificate in palliative care has started. In the first week, we saw the essentials of palliative care. Second week was related to advanced communication skills which is required in the system of palliative care.

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And now, we come down to psychological aspects in palliative care.

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Let us refresh our memory. It was told to you by Dr. Geeta Joshi in the first week that palliative care basically provides holistic care. It gives you physical, spiritual, psychological and social care, holistic care.

Physical basically it relates to pain management and symptom management. Spiritual and social we will see later, but now basically in this week, week number 3, we will be talking about psychological care, what we can provide to palliative care patients.

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### Psychosocial Domains in Palliative Care

- Psychological and Psychiatric
- Social
- Spiritual, Religious and Existential
- Cultural
- Ethical and Legal

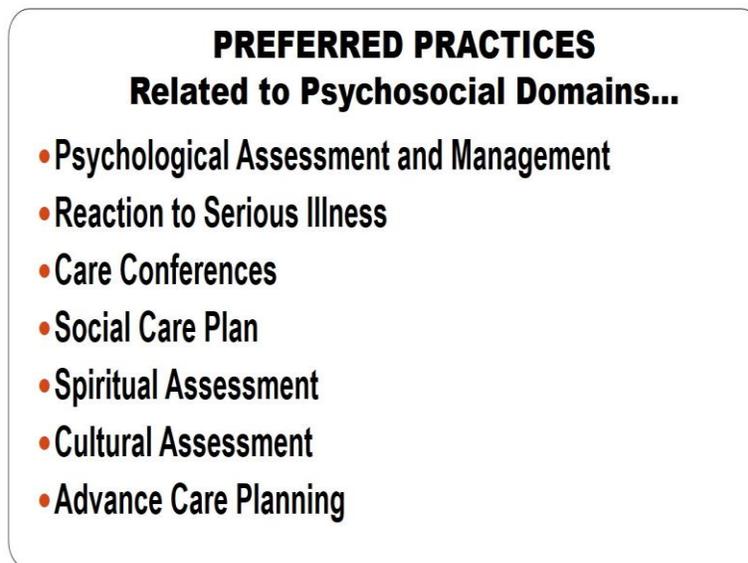
PSYCHOSOCIAL ASPECTS OF PEDIATRIC PALLIATIVE CARE

- Communication with child and family
- Siblings
- Talking about death
- Preparing the family for dying
- Bereavement for family
- De-briefing for staff

What are the psychological domains in palliative care? Anything related with our mind to put it very simply, they are the domains of psychological palliative care, correction palliative care. It is basically psychological and psychiatric, social, spiritual, religious and existential, cultural, ethical and legal. In addition to that communication with child and family, siblings, talking about death, preparing the family for dying and after death comes bereavement for family grief and debriefing of all the stuff.

So, everything all these things come under the domain of psychological social domain.

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**PREFERRED PRACTICES  
Related to Psychosocial Domains...**

- Psychological Assessment and Management
- Reaction to Serious Illness
- Care Conferences
- Social Care Plan
- Spiritual Assessment
- Cultural Assessment
- Advance Care Planning

Related psychological domains, we have the following practices, psychological assessment and management, reaction to serious illness by the patient as well as the family members, care conferences between health professional and the patient, their relatives and caregivers, social care plan in which we consider the social as well as financial aspect of the patient also, spiritual assessment, cultural assessment we will see later in the next week.

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## **Bio-psycho-social & Spiritual Model of Care**

- **Premise:** Illness disturbs relationships both within intrapersonal and outside (extra-personal) the body
- Healing therefore is about restoring right relationships and must include **more than physiological disturbances**
- **Healing is possible even if death is imminent.**

(Sulmasy, Daniel P. (2002) A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life. The Gerontologist)

Another model was also given out in year 2002. They call, they called it bio-psycho-social and spiritual model of care. Here in this particular model, they include everything biological, psychological, social, spiritual everything included in the same model.

The premise was illness disturbs relationship both within interpersonal and outside the body. Therefore, they wanted to include everything in one model and illness disturbs everything within and outside the body. Therefore, what is important is the healing. Healing therefore, is about restoring the right relationship and must include modern physiological disturbances. Healing is possible even if death is imminent.

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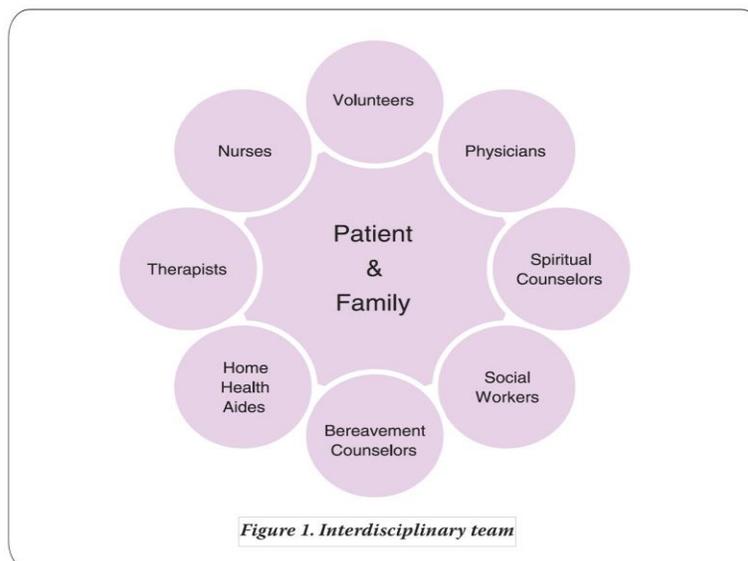
## Bio-psycho-social & Spiritual Model of Care

- Relationship between Mind and Body: relief of pain, nausea, anxiety
- Relationship between Person and Family and Friends: reconciliation
- Relationship between with the transcendent-ability to give/receive love, see oneself as **valuable** even if no longer economically productive

(Sulmasy, Daniel P. (2002) A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life. The Gerontologist)

Relationship between mind and body that is where the relief of pain, nausea and anxiety. Relationship between person and family and friends that is where the reconciliation come up. Normally what happens in our families, in our social background, relations between family and friends you know they are bitter. So just before the death it is time to reconcile and establish peace of mind on both the parties. Then comes the relationship between with the transcendent ability to give or receive love, see oneself as a valuable even if no longer economically productive.

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Ours is a interdisciplinary team. In the center we have patient and family and they are being taken care as one unit. In other disciplines of medical field patient is being treated but here only in palliative care patient and the family members are being treated as one unit and we have physicians, spiritual counselors, social workers, bereavement counselors after death, home head, aides, therapists, nurses, volunteers all this is a teamwork basically.

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### **INTERDISCIPLINARY TEAM FUNCTIONS**

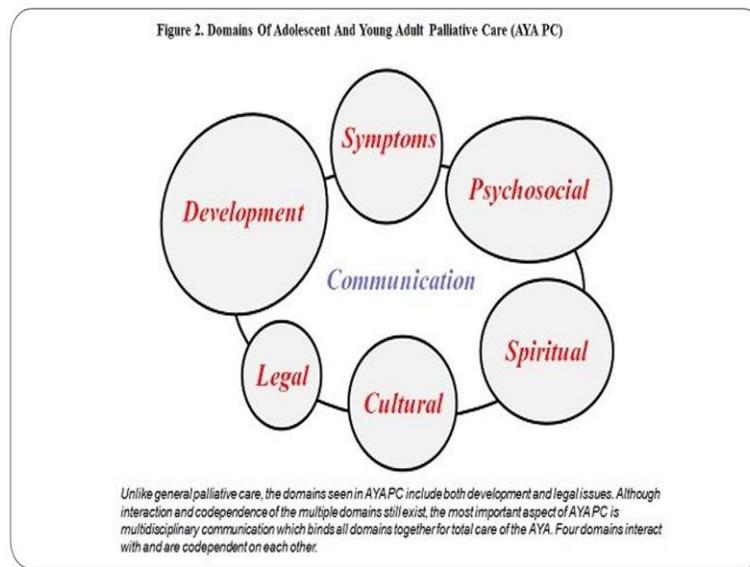
- **Create** Multidisciplinary/interdisciplinary/ transdisciplinary teams.
- **Consults:** Seek information or advice from other Team members.
- **Employee Rounding (Interactions):** It is a system that ensures clear communication and build trust between staff and management. The goals of rounding are to create approachable management, strengthen relationship, find improvement opportunities, and show appreciation to employees.
- **Eliminate Silos (Mindset):** The definition of Silo Mentality is a mindset that occurs in organisations, which is inward looking and resists sharing information and resources with other people or departments within the organisation.

Now how does this interdisciplinary team functions and provides psychosocial care? They create multidisciplinary, interdisciplinary and transdisciplinary teams. Consultation, they seek information or advice from other team members.

Employees rounding off that is interaction between employees. It is a system that ensures clear communication and build trust between staff and management. This particular communication builds trust. The goals of rounding are to create approachable management, strengthen relationship, find improvement opportunities and show appreciation to the employees. Eliminate silos, silos means mindset.

The definition of silo mentality is a mindset that occurs in an organization. Any organization can have mindset. They do not want to change which is inward looking and resist sharing information and resources with other people or departments within the organization and that is how this is what happens in the government also. Government departments they do not cooperate with each other and have very good plans. They start up definitely they start up on the ground but then do not make any headway because one department does not help cooperate with another department. Even ministers also for that matter.

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Domains of adolescent and young adult palliative care. Communication is very important. It is psychosocial, spiritual, cultural, legal, development and symptoms.

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## **EARLY CONVERSATIONS PATIENT & DOCTOR**

- How much do you want to know about your disease and the various treatment options available?
- What past experiences influence your feelings about your care?
- What frightens you most?
- Under what circumstances would you want the goal of care to switch from attempting to prolong life to focusing on comfort?
- What will help you to live with joy and meaning?

(Talking About Treatment Options for Palliative Care A Guide for Clinicians [www.caringinfo.org](http://www.caringinfo.org))

Now what is the early conversation between patient and doctor, in case of psychological care, how much do you want to know about your disease and the various treatment options available to you? Number two, what past experiences influence your feelings about your care? This we need to consider what he has in his mind and accordingly our care plan, our action plan can be prepared.

Third, what frightens you most? Fourth, under what circumstances would you want the goal of care to switch from attempting to prolong life to focusing on comfort? This is what we say we do not want to add days in life, but we want to add life into days. So, this is what we do not want to prolong the life. When we know that end is nearer, it can happen anytime. In that particular case, whatever days are left with the patient, we want that during that time he should feel comfortable, he should be happy and that is what we term as quality of life. This is a very important term.

One of the most important aims of palliative care is to provide quality of life to the patients and particularly to those patients who are nearing the end of their life. What will help you to live with joy and meaning? These two things gives us something to think about, to ponder about. We get certain vision means by means of which we can provide quality of life to the patient and all these things they must come from horse's mouth. That is we must discuss with patient very nicely, gently. We persuade him to give all this particularly what gives him joy and meaning to his life.

So, in those small days of his life, we can give what he wants.

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### **TRANSITIONAL CONVERSATIONS**

- How comfortable are you?
- You told me XXX was important to you-is that still the case? Are there any other things that have come into play now?
- What questions do you have at this point?

(Talking About Treatment Options for Palliative Care A Guide for Clinicians: [www.caringinfo.org](http://www.caringinfo.org))

Transitional conversation, how comfortable are you? You told me so and so was important to you. Is that still the case? Are there any other things that have come into play now? What question do you have at this point? You see normally what happens? We do we have not seen the death. I mean say we ourselves, but otherwise we have seen so many patients. In our family also we see the elderly people, they are at the deathbed.

We attend to them and that is the time that they come up with the last wish. Because this is this is what I would have done. This is what I want to do. So, transitional conversation must come up with the patient. You must follow up that and whatever the patient says, if it is possible that should be that wish, last wish should be completed so that he gets peace of mind before he leaves this world to the heaven above.

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**RICHARD LAMERTON, MD**  
**St. Josephs Hospice, London**

“The aim of the care for the dying patient is to make the body comfortable to live in so that patient (if they desire) can prepare for death mentally and spiritually.”

This is what Lamerton said. The aim of the care for the dying patient is to make the body comfortable to live in. After all whatever happens, we get happiness out of which when our body is comfortable, we feel very happy. We are we enjoy we can enjoy the life. But as and when we get ill, we do not like, we do not we do not want to smile even, we do not want to talk to anyone.

Because body is paining and your total attention is there in that particular region of the pain. So, in such sickness, if you make the patient comfortable by pain management, by symptom management, then patient is little comfortable, he is little happy. And that is the time you can slowly and slowly prepare him for death mentally and spiritually. He will listen to you because he is prepared to listen. He also knows by the way everyone, everyone when we are near the death, we know that you know days are numbered.

Most of the time you also must have seen in your families, in your relatives that some of the people they always say, my dear children, now few days are left you know. So, they also come to know. So, in those few days, if you make them comfortable, then they can take the name of God. Spiritually, mentally they can be prepared. And when they leave, there is nothing, no wish left.

That is what we require. We want to die with santhi (Hindi word meaning calm, peaceful). Asanthi ke shath main banda nahi chaahate (Hindi phrase meaning we want to die with PEACE; no one wants to die with unrest and discord). We want to die with no will, no wish, no desire. And that is the way we can attain sadgati (Hindi word meaning virtue). That is what we say in our Indian culture.

If our mind remains here on some of our wishes, we do not attain sadgati .

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### **Identifying & Addressing Fears of Patient**

- Incompetence
- Death
- Cost
- Mix-Ups
- Needles
- Rude doctors and nurses
- Germs
- Prognosis
- Communication issues
- Loneliness

(<http://www.healthleadersmedia.com/print/MAR-271458/Easing-Patient-Fears-Can-Raise-HCAHPS-ScoresInfection>)

What are the fears of patient at the time of death? Incompetence, death. Death is the most fearful thing, very fearful. Yes, if you are prepared for it, mentally you have prepared yourself for it, then nothing, it just comes. You accept it as such, come take me away.

But otherwise, if your lost desire, wishes still linger on in this social world, then death is very very fearful. Cost, economic background, because death is costing your sickness, it is costing hell of a lot to the family. Lots of money is being spent on the sickness and the same money could have been utilized for the education of the family children. Mix ups, needles, we call lots of injections, rude doctors and nurses, doctors, yes, they are, most of them they are good, gentle, but as it is some doctors are rude also.

They do not treat patients nicely. Germs, maggots, prognosis, communication issues, language they cannot understand, medical jargons they cannot understand. When doctors or nurses try to explain, they cannot understand. And loneliness, this is what we have to suffer, loneliness. Remember dear friends, when we get old, 70, 80, 90, do not think that our children, our sons and daughters are going to be with us. They might be away and might be in a foreign country also.

I know lots of families in Gujarat that parents are staying here, whereas their children are away somewhere in distant part of our country or maybe some of them they are in foreign country. They are lonely. The friends, they are also lonely because they are also of the same age, they cannot travel and meet each other. Even these elderly people they are staying with the children, children are busy with their own families.

They have got the jobs to perform. They go out in the morning, come back in the evening and that is why they do not have time to spend even few minutes with their parents. My advice is this that loneliness is going to be a part of our life when we grow old and it is high time that we learn living on ourselves only. You start living within, this is going to happen and how to accept it, you got to learn certain practices.

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## **LISTEN SILENTLY!**

- Listen for the story behind the story (make visible the underlying values and beliefs)
- Don't just DO something; stand there!
- Be willing to face uncertainty
- Create a space for change and growth
- Avoid platitudes, making comparisons, inappropriate positivity.

In psychology, if you want to understand the psychology of the patient or the family members, again active listening is very important. And this is the time when you know that nothing more can be done about the patient, about his illness.

So, you are not able to cure anything. So, this time you can listen very silently. Silence is also very powerful. When you listen to somebody without single, without uttering a single word, but with full attention, yes that is what is required. The speaker gets lots of satisfaction that we have listened to him properly. Listen silently, listen for the story behind the story.

Let him, if he is able to speak something, let him talk about his life, whatever he wants to say. Do not just do something, stand there. This is what happens normally when you are talking with somebody at that time, you just put your hand in the pocket and take out the mobile and just see which call is this or that. No, this is distraction. When I say listen silently means just be there, be there, do not speak a single word, just there is no requirement of talking to him.

Just be there, doing nothing and looking into his eyes, nodding your head that you are listening attentively. Be willing to face uncertainty. Patient is a patient suffering from so many diseases. Dementia is one thing, forgetfulness. May start with one story and after two minutes, may another story or this or that, you know there is no coherence.

Create a space for change and growth. Avoid platitudes, making comparisons in appropriate positivity.

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**EFFECTIVE FAMILY CONFERENCES**

1. Pre-meeting!	7. Introductions and agenda setting
2. Setting	8. Patient/family explanatory models
3. Participants	9. Anticipate concerns and titrate information
4. Interdisciplinary Team Patient/Family	10. Care plan (with focus on goals)
5. Structure	11. Closing
6. Preparation	12. Follow-up

This is the time in psychological distress that we have family conferences. Because psychological distress, family is also very important part. They are with the patients 24 by 7.

We should have pre-meeting. In the pre-meeting, decide the date and venue, setting participants who will come. The nearest relative, very close people should attend caregivers, particularly family and friends. Then from health professionals, it is the whole team, interdisciplinary, maybe doctor, psychologist, nurse, structure, what is going to be the agenda, preparation, introductions and talk about those agendas. Patient and family, explanatory models, anticipate concerns and titrate information.

Then care plan and this plan must focus on goals. Because now what should we do? This is our goal and we should try and achieve it. Closing and follow up. Without coming down to the goal, creating a goal, do not close up this particular conference. Because the aim of conference is a few days are left and what should we do, what should we produce,

which wish or which will of the patient to be obeyed. This particular goal, how it is to be achieved must come up at the end of the conference and then follow up.

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### **SEATTLE DECISION-MAKING TOOL**

- Medical Indicators
- Patient Preferences
- Quality of Life Indicators
- Contextual Issues

([www.seattlechildrens.org/pdf/Decision\\_Making\\_Tool.pdf](http://www.seattlechildrens.org/pdf/Decision_Making_Tool.pdf))

Seattle decision making tool, it is worth seeing it. I have given the link address. It gives you certain things about decision making, includes medical indicators, patient preferences, what are the indicators of quality of life and co-textual issues.

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### **Facilitating Conversations about Goals of Care...**

- Attend to affect and provide opportunities for patients to talk.
- Avoid vague terms or define them.
- Ask for questions.
- Remind patients that they don't need to make an immediate decision and can always change their mind.
- Ensure shared understanding of conversation by asking why when patients ask for specific treatments or
- Express their goals.
- Restate your understanding and ask for confirmation that you got it right.

Goals of care we are talking about. Attend to affect and provide opportunity for patients to talk. Let him talk. Avoid vague terms to define them. Ask for questions. Remind patient that they don't need to make an immediate decision and can always change their mind when we ask what do you want? What do you want in the balance part of your life? They'll keep changing, this is what I want, let them change it. Ensure shared understanding of conversation by asking why when patients ask for specific treatments, express their goals, restate your understanding and ask for confirmation that you got it right. Every time such thing happens you must restate so that everybody is on the same page. Otherwise some mistakes can occur in communication and what a patient wants and what we deliver can be totally different.

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### **Facilitating Conversations about Goals of Care**

- Remember that you are offering to let people talk about this issue, not forcing them to give up.
- Remember to talk about the positive things that you can do to help the patient accomplish their future goals
- It might help to conceptualize these conversations like going to travel-guides (at least it helps us). You want to find out where they want to go and what they want to avoid. Also find out what they might be
- willing to go through to get to these destinations and how to handle probabilities. Knowing this, you can then make recommendations about the best treatments to help them accomplish this plan.

(Medical Oncology Communication Skills Module 4)

Remember that you are offering to let people talk about this issue, not forcing them to give up. Remember to talk about the positive things that you can do to help the patient accomplish their future goals. It might help to conceptualize this conversation by going to travel guides. At least it help us. Whenever you want to travel somewhere we generally go to the travel people and we tell them yes we want to go to Calcutta or Chennai or Guwahati.

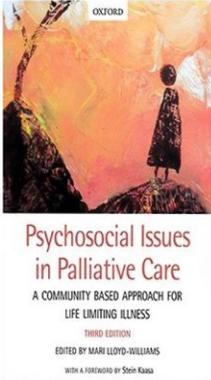
How should we make plans? Where should we stay? So similarly such conversations will also give us some travel plan for the future of the patient. Willing to go through to get to this destination is how to handle probabilities. Knowing this you can then make recommendations about the best treatments to help them accomplish this plan.

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**ADVANCE CARE PLANNING**

1. Advance Directives
2. Five Wishes
3. Caring Conversations

([www.practicalbioethics.org](http://www.practicalbioethics.org)  
Physician Orders for Life-Sustaining Treatment)



We must have advanced care planning also because slowly and slowly the situation of the patient is going to deteriorate from bed to worst and for that we have something known as advanced directive. We will take up this issue of advanced directive in the coming weeks.

Five wishes, this is a very good idea and this particular wishes can be put in one of our goals also for the patient. We must ask the patient what are your five last five wishes now, what do you want to do? You must be knowing that even in jail authorities also when they had go or death had been decided to hang a particular prisoner, they prepared the prisoner. Generally they hang the prisoner early in the morning. So night preceding they ask what sort of dinner you want you know. We will provide you the dinner whatever you want so that you can get peace of mind.

In the last wish nothing else can be given out. So to our own patients, to our own people we can just say what are your wishes now. You can write down also and you can include

them in the final goal and caring conversation this is not the time to fight. He is living, he is living forever. So a conversation with the elderly fellow that patient should be very very loving, forget and forgive whatever he had done to you. Now it is your time to listen to him smilingly and do what he wants. Total care and nothing else.

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## **Palliative Care or Ethics Consult ?**

### **PALLIATIVE CONSULT**

- Medical or patient-care situation
- Staff-family conflict over appropriate care
- Questions regarding withdrawal of medical interventions
- Questions regarding life-prolonging interventions

### **ETHICS CONSULT**

- Ethical concerns regarding consent, decision-making capacity, conflicts of values
- Ethical matters in the care of minors or patients with developmental disorders

You can consult ethics consultant also. We have now we have got palliative consultants in Mumbai, Delhi somewhere. They talk about they give you advice medical or patient care situation, staff family conflict over appropriate care, questions regarding withdrawal of medical interventions. This is yes this conflict does take place between the family members. Some family member will say no we don't want to put now the end is coming nearer.

We want to keep our father or our elderly person here at our home only. He must die in our home in front of our own eyes. If we put him in the hospital, he will remain in the ICU and not be able to see, he will not be able to talk to him at all. So some people they say no we don't want to take him to the hospital.

Somebody will say we want to take him to the hospital. We can try. So such conflict do arise in the family and you have to get resolutions of such conflict as early as possible

and that is possible by good and effective communications. Question regarding life prolonging intervention. No need. At the age of 90, an elderly fellow goes to the bathroom, falls down and he fractures his number of bones starting from hip to the joints and other things you know. Now at the age of 90 when there is no blood, there are no muscles in the body and then you take him for the operation, I mean so it is not advisable at all.

What is he going to do? You are putting under lots of pain. So such interventions from your side you may think that he might get okay and might leave, my dear friend firstly to is he capable of going under such heavy surgeries. So such medical and therefore in palliative care we always say that in such life limiting diseases, there is no purpose to increase few days in his life. If he lives by 5-6 days more in the life and that too in the hospital, how does it make any difference to him? Most of the time he will remain unconscious, he will not be able to speak to anybody. So be wise, be little reasonable, do not be too emotional because one has to go, so he has to go and let him go peacefully without giving further pains of operations and postoperative pains. Ethics consult, ethical concern regarding consent, decision making capacity, conflict of values, ethical matters in the care of minors or patients with development disorders.

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## REFERENCES

- Resources, Policies and Tools for Hospital Palliative Care Programs-Crosswalk of NQF Preferred Practices [www.capc.org](http://www.capc.org)
- Caring Connections information sheets [www.caringinfo.org](http://www.caringinfo.org)
- Fast Facts and Concepts-End of Life/Palliative Education Resource Center [http://www.eperc.mcw.edu/fastFact/ff\\_223.htm](http://www.eperc.mcw.edu/fastFact/ff_223.htm)
- National Quality Forum Preferred Practices for Palliative and Hospice Care Quality
- Mike Harlos MD, CCFP, FCFP Professor and Section Head, Palliative Medicine, University of Manitoba

These are the references. So these are the psychological aspects of palliative care. We will take them one by one in the following lectures. Thank you. Thank you dear friends.