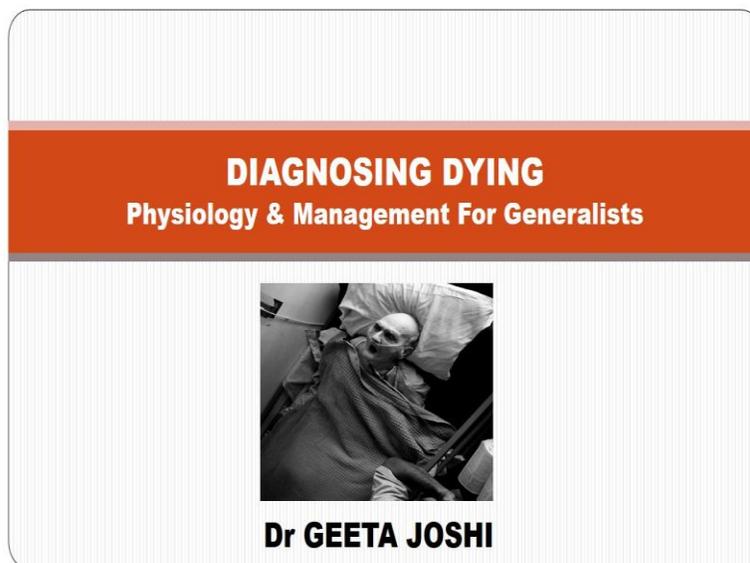


Basic Certificate in Palliative Care
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Week-10
Lecture 03: Diagnosing the Dying!

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This is week number 10, lecture number 3. Namaste (Hindi word meaning greetings). Now we are going to discuss how to diagnose a dying person. Fortunately many of us might have not seen a person dying as today in today's medical scenario most of the patients die in ICU where relatives are separated from the patient, relatives are sitting outside and patient is left alone in AC room with many gadgets around and only nursing staff and paramedical staff around. So, sometimes a person does not know that his or her relative who is sick is now dying and he is he is in last phase of life or maybe few hours away from death.

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OVERALL MESSAGE

- Diagnosis and management of dying is an overlooked aspect of medical care.
- The family's perception of the process can have long-term consequences.
- Dying is not inherently uncomfortable.

So overall message of this lecture is diagnosis and management of dying is an overlooked aspect of medical care.

The family's perception of the process can have long term consequences. If a person who is dying is in distress, he is suffering then family will remember this episode throughout their life and they will have long term consequences psychological problem because of this. So the usually family remembers the last days particularly when it is spent in pain or suffering then it is difficult for them to forget about all these painful incidents and live life ahead. So dying is not inherently uncomfortable always dying death is not always uncomfortable, not always painful or not always so full of suffering. It can be a silent natural process as well.

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ANTICIPATORY GUIDANCE LAST HOURS

- Everyone will die
 - < 10 % suddenly
- Unique processes & risks
- Little experience



Fact is everyone will die but only less than 10% die suddenly. So rest of the people they have a unique risk of suffering pain, pain or some distressing episodes events and most of us has got very little experience about this.

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Anticipatory Guidance Complicated Bereavement

- Hx (History of Patient)
complicated bereavement
- Psych Hx / Dependent
personality
- Out of life-cycle norms
- Poor social support
- Absent frame of reference
- Sudden/violent death



So complicated bereavement takes place when the patient dies within suffering. History of patient will tell you whether this patient is like this patient's family is likely to have complicated bereavement or not. Psychological history and dependent personality are the

people who cannot withstand such event and they have psychological consequences following it.

Some of the people die out of normal life cycle norms they get some very incurable disease like cancer or HIV AIDS or some neurological problem and many of them might have a poor social support and some may have a sudden and violent death as well. So whether you are at risk of such death or not that can be evaluated by your history or a disease related history your other psychological related history and seeing your social background.

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Case Scenario

- Ms A, 84 year mother of two in the ED with cough/PNA
- Accompanied by 62 year daughter
- PMHx: Alzheimer dementia, distant Hx of curative lumpectomy for breast cancer, HTN, osteoarthritis

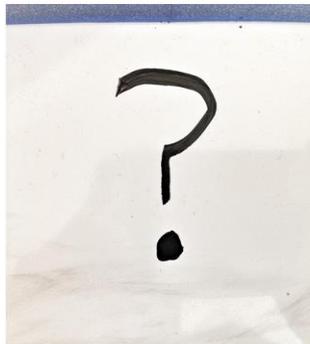


Here is a case scenario Ms.A, she is 84 years mother of two children she comes in a emergency department with cough and paroxysmal nocturnal angina. She is accompanied by her 62 years old daughter. Past medical history is suggestive of Alzheimer dementia and distance history of curative lumpectomy for breast cancer hypertension and osteoarthritis.

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Case Scenario (con't)

- Presently: hypothermic, low white count, left shift; CXR with bibasilar atelectasis vs. consolidation
- You admit her and start IV Abx
- **What else do you need to know?**



Presently when patient comes in emergency department she is hypothermic she is having cold extremities, low WBC white cell count, left shift of x-ray chest, with x-ray chest with bilateral basilar atelectasis may be suggestive of consolidation. Patient is admitted and started on IV antibiotic.

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Discuss Ms A (~10 minutes)

- Mitchell Score (6mo mortality in NH residents with AD): 12.5, 70% 6mo mortality
- Based on PPS: 8-40 days
- How many have the knowledge to be able to describe the process of dying?
- How many of you feel confident describing dying to patients & family?

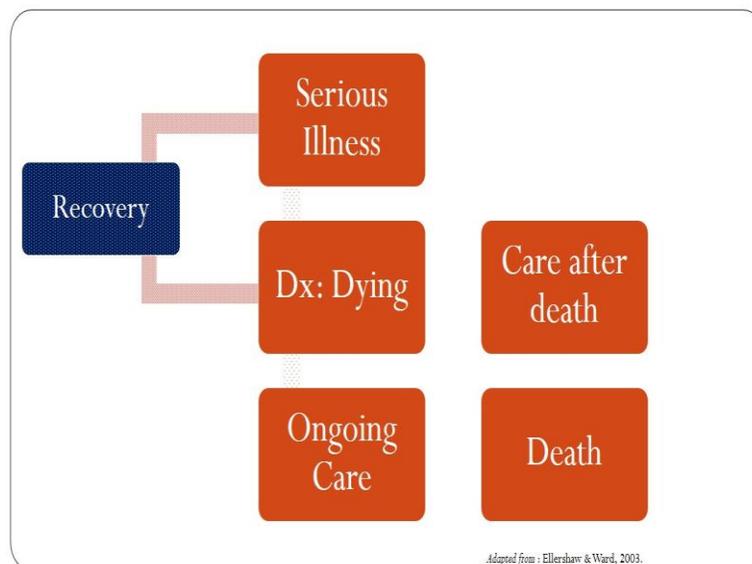


What else you want to know about this patient? You will like to know this type of patient how they are going to die. So discuss this with Ms.A in 10 minutes and it has been

reported that this type of patient if you get this type of patient 70 percent of them die within 6 months of their event. So, based on palliative prognostic scale the life expectancy of this patient is 8 to 40 days.

Now can you describe the dying process for this patient? Can you describe this to his family her family patient's family that how this patient is going to die? The answer is no, because as a medical professionals also we have very less knowledge about dying process and how exactly the death occurs. So, first of all to describe the dying process one should know the diagnosis of the patient and anticipatory guidance what what is likely to happen to this patient because of this disease particular disease what are the likely complications and what are the likely events we consequences which can occur in patients life. What type of environment patient is living assessment of the patient with his comorbid conditions and and acknowledge the fear what patient and relatives has feared about you acknowledge that fear and address their fear as well.

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So, recovery from serious illness may be possible, but if you diagnose that patient is dying you have to prepare the relative you have to prepare the relative for care after death and you have to explain them in spite of patient dying you have to continue the ongoing care whatever care you are giving to the patient maybe nursing care maybe oxygen,

attending personal hygiene, attending feeding and also to should continue and death may occur and following death prepare the relative for care after death. This is exactly the process of die, recovery from the disease either from the serious illness or from any other natural illness.

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Normalize the Environment

- Family presence
- Turn off monitors
- Minimize procedures
- Stop oxygen
- Include pt in conversations
- Touch



First of all when the patient is dying you should normalize the environment there should not be any stress or tension or very fearful environment is created in the surrounding of the patient. With consent of the relative you can turn off the monitors, minimize the procedure, whatever procedure you are doing like sending some investigations or putting up the some IV cannula or injecting some drug and also thing you should minimize. Stop oxygen and include patient in include patient in conversation if patient is awake and conscious try to speak to patient and touch a compassionate care or touch to the patient is very important at this stage of the patient's life.

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Assessment: Comfortable?

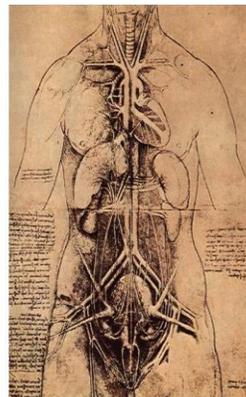


Assess whether patient is comfortable or not.

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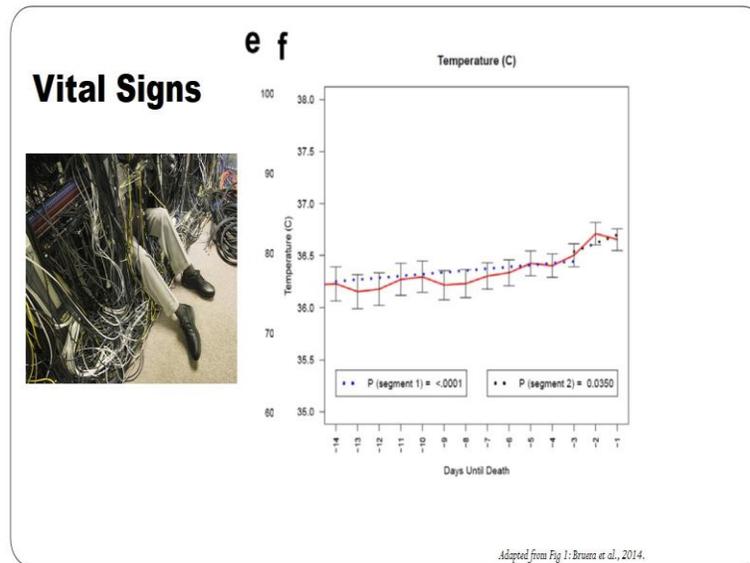
Physiology of Dying

- Cardiovascular
- Renal
- Respiratory
- Gastrointestinal
- HEENT
- Constitutional
- Neurological



Coming to physiology of dying, the dying can start from any of this system. Dying can start from failure of the cardiovascular system, failure of the renal system, failure of the respiratory system, gastrointestinal system, head, eye, ear, nose and throat anywhere or constitutional from just we inside suddenly the heart stops and patient dies or neurological system.

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So, what happens to the when when the physiology of dying starts what you are assessing are the vital signs that is temperature, pulse, blood pressure and oxygenation. Coming to blood pressure it steadily goes down initially you may be able to measure blood pressure over here after that you may not be able to measure when it comes to less than 90 or 70 or like that, but you will be able to feel cold clammy extremities hands and feet of the patients becoming cold and this shows the blood pressure is going down. Heart rate goes up to compensate the blood pressure there will be tachycardia and it may reach up to 140 pulse per minute. Oxygen saturation as the breathing becomes inefficient to maintain the oxygen into the blood the saturation will go down starting from 90, 85 then going down all the way to 60 and below that that shows now patient is dying his respiration is failure. Temperature as I suggest said earlier temperature will go down in few cases where there is a lesion in the central nervous system patient might have very high fever also while dying.

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CONSTITUTIONAL

- Terminal fever
- Pressure ulcer risk
- Symptoms: Weakness; Fatigue; Joint position fatigue



So, terminal fever also can be present in a few of the patients. Pressure ulcer risk when patient is dying for prolonged many days he is lying in the bed and dying slowly and slowly there is a risk of getting pressure ulcers. Patient will feel very very weak fatigue joint position or particular positions will be taken up by the joints and movement is impossible.

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FEVER

- **Fears:**
Suffering, Hastened death
- Management
 - Noninvasive cooling
 - Rectal acetaminophen

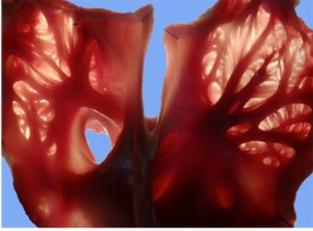


Whenever a dying patient gets fever relatives are very very apprehensive they feel that this is fever means suffering it enhances it adds to the suffering of the patient and this will hasten the death of the patient. So, here you can give non-invasive cooling like application of sponge, cold sponging all over the body on the larger surface area of the body like abdomen extremities head neck etcetera and if patient is not able to swallow you can give paracetamol by rectal route. So, this is to bring down the fever and speak to relative to minimize their apprehension, explain them about the fever and do the best possible without much intervention.

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CARDIOVASCULAR

- Tachycardia, hypotension
- Peripheral cooling, cyanosis
- Third-spacing
- Mottling of skin...
- Symptoms: dizziness, edema



When the dying is because of the cardiovascular failure there is usually tachycardia and hypotension and peripheral extremities are cold and extremities nails are blue that suggesting of sinuses. This suggest there is a poor circulation into the limbs or periphery of the body and limbs are becoming cold, commie extremity with sinus nails. So, all circulation volume circulatory volume instead of being in inside the blood vessel it goes outside the blood vessel or we call it third space and there will be a mottling of the skin a potential hemorrhage like on the skin and patient will complain of dizziness and edema, patient will complain of swelling of the feet, swelling of the hands and patient will feel dizzy.

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MOTTLING



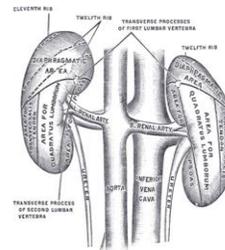
- Sign of diminished cutaneous perfusion
- Variably present

This is the sign of mottling which is the sign of diminished cutaneous perfusion where cutaneous the blood supply to the periphery skin and also tissue is diminished extensively drastically.

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RENAL

- Decreasing urine output
- Diminished GFR (changing pharmacokinetics)
- Symptom: generally comfortable



When the dying is because of the renal failure kidney failure there will be decrease in urine output there will be decrease in glomerular filtration rate that is function of the

kidney and this will change the pharmacokinetics of many drugs. So, whatever drug you are giving you have to give half the dose because their action will be prolonged and side effect will be very maximized. So, change the dose of the drug in case of renal failure, but otherwise patient is generally comfortable he might be having some edema feet, but otherwise patient does not have much symptoms.

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PAIN
continuous opioids & Oliguria

- <math><20\text{ml/hr}</math> (500ml/d):
decrease
- <math><10\text{ml/hr}</math> (250ml/d):
stop!
- Always: bolus for
symptoms



If dying is because of pain continue opioids even in renal failure which is associated with pain continue opioids even in presence of oliguria means when patient is not able to pass urine. Here you can decrease the dose and stop whenever patient is pain free and always give small bolus doses instead of infusion.

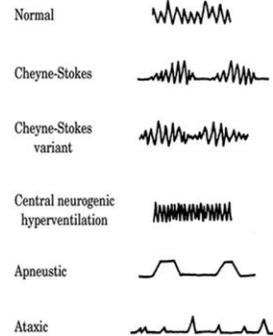
If you give infusion it is likely to get drug likely to get accumulated into the body, but if you give small bolus dose intermittently as per requirement it will achieve the symptom management and relief of pain.

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RESPIRATORY

- Patterns:

- Tachypnea, Apnea
- Chin-lift, jaw-jerk*
- Diminishing tidal volume
- Oropharyngeal secretions*
- Symptoms: generally comfortable

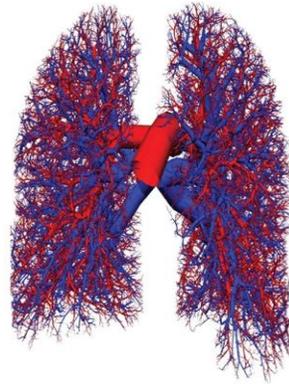


If dying is because of the respiratory failure on right side you can see the different respiratory patterns which will be exhibited in the patient who is dying of the respiratory failure. So, patient might have tachypnea, fast breathing, apnea means intermittent slow breathing, chin lift, jaw jerk, diminished tidal volume very short breath patient will take, oropharyngeal there will be lots of oropharyngeal secretion collection and otherwise patient is comfortable except for the whenever patient is tachypneic he becomes more restless otherwise he is comfortable. Patient might have Cheyne-Stokes breathing, Cheyne-Stokes is waxing and waning few few seconds or minute he will take fast breath then suddenly slow breath then again fast breath that is called Cheyne-Stokes breathing.

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CHANGES IN RESPIRATION

- Fear:
 - suffocation
- Management
 - Family support
 - Oxygen variably effective
 - Opioids



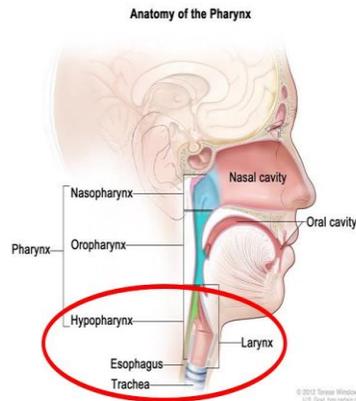
So, whenever patient is dying because of respiratory failure and there is change in respiration, like respiration becoming very fast or very slow then there is a fear and apprehension in the patient if patient is conscious and relative that patient is getting suffocated and this feeling is very terrible and that very fearful and that death is approaching.

In this case you manage the family by providing support explaining them the situation oxygen may be given that may have placebo effect, but sometimes it helps to console the family and patient and give small dose of opioid to take out the unnecessary breathing and take out the dyspnea and tachypnea. So, this will make the patient as comfortable as possible.

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SECRETIONS

- Fear:
- Choking, Drown
- Management
- Reassurance
- Positioning
- Glycopyrrolate



Many a times dying patient cannot swallow secretions. So, whatever saliva or everything is collected into the oropharynx or sometimes patients relative keep on giving them fluid or gangajal (Hindi word meaning Ganga water) or some water then this secretion becomes noisy with each respiration and it is called death rattle which we have talked about in other lecture. So, here patient and relative will feel that patient is getting choking sensation and he is drowning in his own secretion.

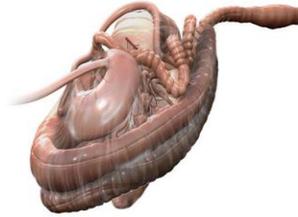
The management is reassurance, positioning of the patient, turn the patient on one side. So, the secretion will drain out clean the secretion with goes on the finger or by suction on you can give injection glycopyrrolate 1 ampoule intramuscular to dry out the secretion.

So, these are the this thing, here are the secretions which gets collected and here is the larynx through which air passes during respiration and that makes noise when the air is passing through the collected secretion pool of secretion at the back of the tongue then it gives death rattle. This is the hypopharynx where the secretion will get collected.

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GASTROINTESTINAL

- Loss of ability to swallow
- Dehydration
- Ileus
- Symptoms: anorexia;
nausea; dry mouth;
incontinence



Certain during dying process there are certain changes in gastrointestinal system.

Patient loses the ability to swallow because of the weakness of the neck muscles and oral cavity muscles. So, that will lead to dehydration. Paralytic ileus, small intestine stops working it becomes lifeless, listless there is no movement. So, there will be distension of the abdomen gas like feeling and usually few days before death patient has anorexia, nausea, dry mouth and incontinence of the stool or urine. So, these are the symptoms.

So, patients family really get worried that usne khana chhod diya hai (Hindi phrase meaning He/She has stopped eating). In our social system khana (Hindi word meaning food) is linked with life. Eating food means you are surviving and if you are not eating food you are dying. This may be true to some extent, but as the body is dying, the requirement of the food and everything decreases. So, this is and then relatives are bent upon feeding the patient at any cost.

So, here we explain the relatives that now body's requirement is very very low, body does not need food that is why he is not eating and that is how we try to convince the patients relative that he will that we should not give any food or liquids forcefully to this type of patient. I remember an incidence young boy about 12 years old he was dying of cancer of bone osteosarcoma in our hospital. He was almost terminal last few days or hours were left and, but he had severe pain and he was restless. So, we gave him a injectable opioids

and other analgesics, but then patients relative decided to take patient home and they were staying in nearby village which was about 100 kilometers away from the institute. And so we explained the patient's mother about the sedation to make him sedated and be comfortable because otherwise if he is awake he is very restless because of pain and all.

So, mother's worry was only one that if you sedate him and if he is thirsty and ask for water he will not be able to express that he wants water while he is dying and I will not be able to give him water. So, do not sedate him this was the he her main concern was. So, that is our belief that dying person should be given water or something. So, he is all wishes are fulfilled till last, but it is not the not so as the person who is dying his requirements becomes very very less.

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DECREASING FOOD INTAKE

- Fear:
- Starvation
- Management
 - Normalize & Reframe
 - Food for comfort
 - Aspiration risk

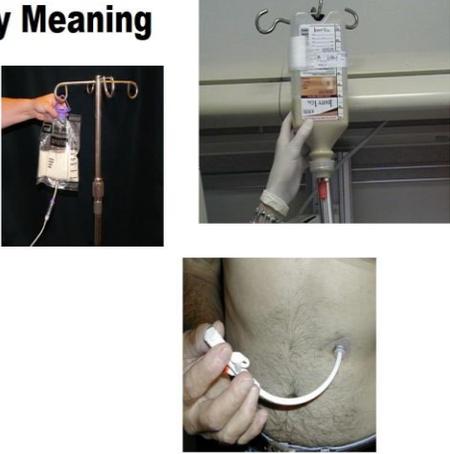


This we talked about that when the food intake decreases there is always fear that patient will die of starvation. So, always try to normalize the feeding if patient is conscious and all, try to give, feed if possible or very small sips of water or sips of some liquid or juices can be given. But you should always check the risk of aspiration, you should feed only to the conscious patient any patient who is disoriented or does not have ability to swallow should not be given any food or liquids otherwise he will aspirate it will go into the wind pipe.

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Patient/Family Meaning

● “Food” = ?



The slide contains three images. The top-left image shows a hand holding a clear IV drip chamber connected to a tube. The top-right image shows a hand holding a drip chamber with a label. The bottom image shows a hand holding a white nasogastric tube inserted into a patient's abdomen.

Try to understand patient and family's meaning of food. Sometimes they mean that if patient is not eating you give some intravenous fluid or some feeding by other means. Regarding giving intravenous fluid to a dying patient there are many disadvantages rather than advantages.

So, we explained the patients and relative regarding this. A dying patient and hypothermic patient and patient in shock, patient being breathless if our patient having abdominal distension if they are given IV fluid it will worsen the situation. It will make him more breathless as more fluid will go into the lung and will cause him breathlessness. It will increase the distension of the abdomen and he will become more in discomfort and after all this IV fluid is not going to prolong his life. After all it will come and if patient in kidney failure given IV fluid you will overload the circulation and make him breathless. So, all these factors are explained to the patients relative and convince them that this type of patient does not need a even if they are not taking food there is no need to give food by intravenous means or through tubing's or through IV fluids.

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Patient/Family Meaning

- No! “Food” =



And usually patient and family means, food means eating on the dining table and all these thing, but no we have to tell them that this is not the only means way the food can be given and it should not be given.

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DECREASING FLUID INTAKE

- Fears:
 - Thirst
- Management
 - Reassure
 - Benefit/Burden of IVF
 - Oral care



Patient decreasing in fluid intake as I we discussed earlier the apprehension of the family that he will die of thirst. So, again reassurance, benefits and burden of IV fluids as we already discussed and oral care that oral care should be given that will enhance some

watering into the mouth and patient will feel thirsty and can be given few spoons of liquids whatever is he needs.

Head eye, ear, nose and throat what happens to that when patient is dying? Usually eyes are open, loss of retro orbital fat pad, insufficient eyelid length, slack mouth and symptoms like dry there will be dry eyes and dry mouth when patient is drying.

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Xerostomia / Xerophthalmia

- Fears:
 - Thirst, Suffering
- Management
 - Oral care
 - Eye care



So, when relative sees the dry mouth they feel he is dying because of thirst and he is suffering. So, you can put a gauze wet in saline over the mouth of the patient, you can make you little bit oral care and eye care when if the eyes are dry you can put some drops and cover the eyes.

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NEUROLOGICAL

- Progressive decrease in LOC
- Preserved hearing & touch
- Delirium
- Pain not automatic!
- Symptoms: Confusion;
Drowsiness



If patient is dying of neurological problem in central nervous system problem, there will be progressive decrease in consciousness, but hearing is preserved touch is preserved. So, I have seen many of the relative talking in the ear of the patient and saying spiritual mantra or some messages to the patient and, but touch is identified. So, always patients relative can touch the patient give compassionate touch, hold the hands, Mata ke haath pair chhu sakte hain (Hindi word meaning one can touch the feet of the mother).

Patient might be in delirium because of the neurological problem and the treatment of delirium we had already discussed in one of the lecture you may have to sedate the patient finally, if delirium is very agitating and disturbing to the relative. Sometimes patient may feel pain and there is a confusion and drowsiness when patient is dying because of the neurological consequences.

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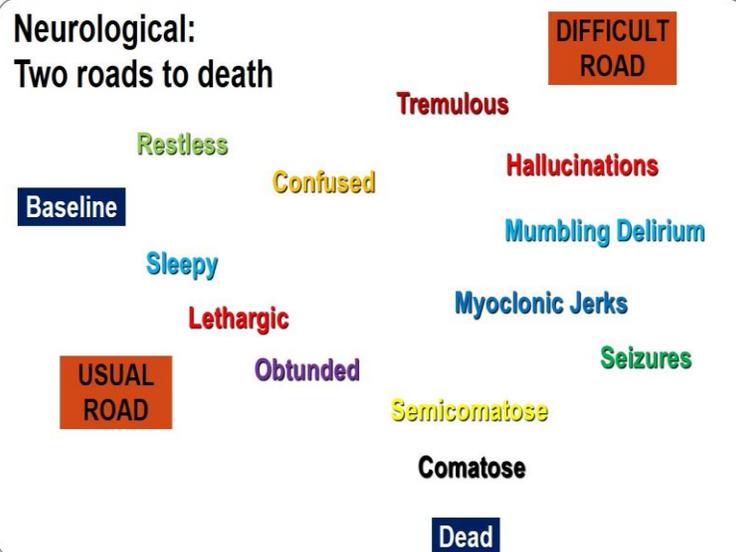
PAIN

- Fear:
 - Uncontrolled pain
- Grimace
- Physiologic signs
- Incident vs. rest pain
- Differentiation from delirium



If a dying patient is in pain, patients relative do feel that he is dying in pain because of pain and what are the signs? There will be grimace on the patients face, patient will be aggressive agitated, there are physiological signs of pain, like increase in pulse rate, increase in blood pressure, increase in respiration. This pain may be may have come suddenly or it that was already existing before the dying process started. So, differentiate is from delirium and try to control pain with opioids either given orally sublingually or by subcutaneous route or even rectal route it can be given.

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So, with neurological complications the death can choose two days, two roads one is usual road, neurological patients slowly will become semi conscious, sleepy, lethargy, obtained dead then semi conscious, comatose then comatose and dead. Second route is very difficult road here the patient will become restless, confused, tremulous, hallucinations, delirium, myoclonic jerks, seizures all such very disturbing sign symptoms will occur and as a palliative care physician you have to control all this with medicine either given subcutaneously, sublingually or through rectal route.

So, this usual road is ok peaceful, welcome, but this difficult road remains in memory of the patient's relative and it is difficult for them to accept this they feel their loved one is died in pain, in suffering and in agitated way.

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TERMINAL DELIRIUM

- Fear:
- Terror
- Management
- Diagnosis
- Consult me.

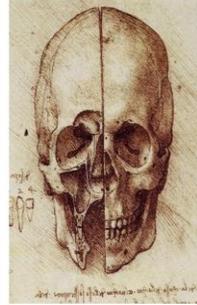


Terminal delirium is very terror that it is very very disturbing patient will be agitated he will talk irrelevant maybe that time he talks something from past and relatives become so upset that he is remembering such past event or some very fearful event or unwanted event of the past. Then sometimes patient gets up and throws away everything takes out his clothes and all and all these things is very fearful in this case always have a proper diagnosis and treat the delirium as early as possible by opioids, benzodiazepines and haloperidol.

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AFTER DEATH

- Cardiopulmonary arrest
- Eyes often open
- Pupils fixed
- Jaw open
- Waxen pallor
- Muscles, sphincters relax



Once the death occurs there is a cardio respiratory arrest, cardiac function stops, respiration stops. So, first sign you can observe is respiration has stopped then you try to see the look for the pulse, but you should always look for the pulse at in the higher vessel larger vessels in neck or in femoral region. Then you see the eye, check the eye for pupillary movements and pupils are dilated and fixed that shows that patient is dead. Eyes are usually open pupils are fixed, jaw is open, pallor absolute pale extremities, muscle and sphincters sometimes gets relaxed at after death and patient will evacuate urine and stool.

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Pronouncing death

- “ Please come... ”
- Entering the room
- Pronouncing
- Documenting



How we will declare death as doctor Yashwant Joshi also said that certain things you have to discuss not in corridor, but in doctors cabin or a separate counseling rooms are there in palliative care setup.

So, you can call near ones relatives and in presence of you and your colleague or some paramedical staff you can say declared the death they whatever word suits you. Not like that, Oh toh mar gaya, yeh se nahi (Hindi phrase meaning not like telling he just passed away) but he is no more or he has travelled to a heavenly abode or whatever good words you can choose for. And at the same time you have to document the death, you have to give death certificate to the relative and take their signature when you hand over the dead body to the relative.

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OVERALL MESSAGE

- Diagnosis and management of dying is an overlooked aspect of medical care.
- The family's perception of the process can have long-term consequences.
- Dying is not inherently uncomfortable.

So, overall message is diagnosis and management of dying is an overlooked aspect of medical care. Usually when the patient is serious about to die doctors go away and leave the relatives alone with the patient or sometimes a junior staff is left alone with the patient who does not know how to communicate with the patient's relative. This is the sometimes scenario in very busy hospitals, but as a medical professional it is our duty to learn how to face this situation and how to make relatives understand and face the situation and support them.

Family's perception of the process can have long term consequences. So, if this process is very much prolonged and agitated family will have lots of long term consequences. Dying is not inherently uncomfortable sometimes the death are peaceful and sometimes you can make death peaceful by giving proper treatment, by giving proper infusion and drugs and make the patient comfortable and quiet while he is dying. Thank you very much.