



**Ian Anderson Continuing Education Program
in End-of-Life Care**

Module 7

THE LAST HOURS



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Case Scenario

Julian Smithers is a 68-year-old man with non-small cell lung cancer diagnosed 9 months ago. He had radiotherapy to a large hilar mass at the time of diagnosis. He was relatively well for 2 months when he developed thoracic back pain. This was secondary to bone metastases and spinal cord compression. He received further radiation and morphine for pain control. He is now on 260mg of sustained release morphine every 12 hours with reasonable pain control. Other symptoms include anorexia and cachexia, generalized weakness and mild dyspnea.

You have followed him regularly. He lives with his wife Linda in a 2-bedroom condominium. They have 4 married children – 2 sons and 2 daughters – and 6 grandchildren. One son lives in Texas and the other children live nearby. Julian worked for a small manufacturing firm. Linda, who is 60, took early retirement from her civil service job when Julian developed cancer. The local home care program is involved and a nurse visits twice a week.

Linda and Julian have discussed the illness with you on multiple visits. He has indicated that he would like to die at home.

Introduction

- ❑ The last hours of living module incorporates a comprehensive approach to providing care to patients who are in the last hours or days of life and their families.
- ❑ Careful management in this final phase can lead to smooth passage and healthy grief and bereavement.
- ❑ Every one of us will die. A few of us (<10%) will die suddenly. Most of us (>90%) will die after a long period of illness with gradual deterioration until an active dying phase at the end.
- ❑ The last hours of our lives may be some of our most significant. They provide the last opportunity to finish our business, create final memories, give final gifts, find spiritual peace, and say good-bye.
- ❑ Those who provide care have one opportunity to get it right. There is no second chance.
- ❑ If managed carefully and well, the last hours can lead to significant personal and family growth.
- ❑ If managed poorly, life closure may be incomplete, suffering may occur unnecessarily, family distress may continue long after the patient's death, and those who watch may worry that their death will be similar.
- ❑ Most of us have little or no experience with the dying process or death. While many professionals have seen a dead body, lay people rarely have. Most of us have neither watched someone die nor provided care during the last hours of life.
- ❑ Based on media dramatization and our vivid imaginations, most people have developed an exaggerated sense of what dying and death are like. However, with appropriate management, it is possible to provide the usual smooth passage and comfort for the patient and all onlookers.

Objectives

The participant will be able to describe:

1. The importance of this phase of a patient's illness.
2. The signs and symptoms of impending death.
3. A care plan for the following signs and symptoms:
 - ❑ Weakness and fatigue.
 - ❑ Secretions.
 - ❑ Pain.
 - ❑ Skin care.
 - ❑ Delirium and agitation.
 - ❑ Incontinence.
 - ❑ Dyspnea and respiratory changes.
 - ❑ Dry membranes.

4. The psychosocial and spiritual issues in the last hours and a management plan to address those needs and expectations.
5. The initial bereavement counseling issues for the family.

The **CAR_xE** Approach¹

Comprehensive Care Considerations

- ❑ The importance of the final hours is independent of the proposed site of dying.
- ❑ All issues – physical, psychological, social and spiritual need to be addressed.
- ❑ During the last hours of their lives, all patients require skilled care around the clock. This can be provided in any setting as long as the professional, family, and volunteer caregivers are appropriately prepared, educated and supported throughout the process.
- ❑ The environment must allow family and friends access to their loved one around the clock without disturbing others and should be conducive to privacy and intimacy.
- ❑ Medications, equipment, and supplies need to be available in anticipation of problems, whether the patient is at home or in a health care institution.
- ❑ As the patient's condition and the family's ability to cope can change frequently, both must be reassessed regularly and the plan of care modified as needed. As changes can occur suddenly and unexpectedly, caregivers must be able to respond quickly. This is particularly important when the patient is at home, if unnecessary readmission is to be avoided.
- ❑ If the last hours of a person's life are to be as rewarding as possible, advance preparation and education of professional, family, and volunteer caregivers is essential, whether the patient is at home, in an acute care or skilled nursing facility, a hospice or palliative care unit, prison, etc.
- ❑ Everyone who participates must be aware of the patient's health status, his or her goals for care and the parents' goals if the patient is a child, advance directives, and proxy for decision making.
- ❑ They should also be knowledgeable about the potential time course, signs and symptoms of the dying process and their potential management.

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- Help families to understand that what they see may be very different from the patient’s experience. Explore ways they can be involved in the care if they wish. If family members and caregivers feel confident, the experience can provide a sense of final gift giving.
- For parents of a dying child, confidence can leave a sense of good parenting.
- If unprepared and unsupported, they may spend excessive energy worrying how to handle the next event. If things do not go as hoped for, family members may live with frustration, worry, fear, or guilt that they did something wrong or caused the patient’s death.
- Physicians will need to establish in advance whether potential caregivers, including professionals who work in institutions, are skilled in caring for patients in the last hours of life. Do not assume that anyone, even a professional, knows how to perform basic tasks.
 - Those who are inexperienced in this particular area will need specific training including, for instance, knowledge about body fluid precautions. Written materials can provide additional support to caregivers when experts are not present.
- Although we often sense that death will either come quickly over minutes or be protracted over days to weeks, it is not possible to predict when death will occur. Some patients may appear to wait for someone to visit, or for an important event such as a birthday or a special holiday, and then die soon afterward. Others experience unexplained improvements and live longer than expected. A few seem to “decide to die” and do so very quickly, sometimes within minutes. While we may give families or professional caregivers an idea of how long the patient might live, always advise them about the inherent unpredictability of death and the usual course of a comfortable and peaceful death.
- The absolute necessities in the last hours include:
 1. Family & care provider education.
 2. Multidisciplinary teams with 24-hour rapid response capability.
 3. Adequate pain and symptom control.
 4. A written care plan.
 5. Institutional backup if the patient is at home.
 6. Enough help to avoid family exhaustion.

Assessment

The Signs and Symptoms of Impending Death

1. Rapidly increasing weakness and fatigue.

- Weakness and fatigue usually increase as the patient gets closer to death. In the last hours of life, it is likely that the patient will not be able to move around in the bed or raise his or her head.
 - At the end of life, fatigue need not be resisted and most treatment to alleviate it can be discontinued
2. Decreasing intake of food and fluids.
 - Most patients lose their appetite and reduce food intake long before they reach the last of their lives. There are many causes, most of which become irreversible close to death (see module on [Symptom Management](#)).
 - Families and professional caregivers may interpret cessation of eating as “giving in.” They frequently worry that the patient will “starve to death.”
 - This decrease in fluid intake is accompanied by decreased urine output and dry membranes.
 3. Difficulty swallowing with loss of gag reflex.
 - In the last hours of life, weakness and decreased neurologic function frequently impair the patient’s ability to swallow.
 - The gag reflex and reflexive clearing of the oropharynx decline and secretions from the tracheobronchial tree accumulate.
 - The mouth is often open and the jaw falls posterior with narrowing of the airway, which may exacerbate difficulty clearing secretions.
 - These conditions may become more prominent as the patient loses consciousness. Buildup of saliva and oropharyngeal secretions may lead to gurgling, crackling, or rattling sounds with each breath.
 - Some have called this the “death rattle,” a term frequently disconcerting to families and caregivers. For unprepared families and professional caregivers, it may sound like the patient is choking.
 4. Decreasing level of consciousness.
 - The majority experience increasing drowsiness, sleep most if not all of the time, have limited periods of being full awake and lack of interest in surroundings.
 - Decreased or absent blinking is common leading to drying of the conjunctiva and possible discomfort.
 - They may eventually become unrousable i.e. comatose.
 - Absence of eyelash reflexes on physical examination indicates a profound level of coma equivalent to full anesthesia.
 - Reflex activity
 - Grasping hands.
 - Clenching teeth on swab.
 - Moaning with movement, position change, each breath out.
 5. Terminal delirium or agitation.
 - Delirium may be the first sign to herald the “difficult road to death” for a minority of patients.
 - It frequently presents as confusion, restlessness, and/or agitation, with or without day-night reversal.

- It may result from any of the standard causes of delirium listed in DSM-IV (American Psychiatric Association, 1994) that can accompany the dying process.
 - Agitated terminal delirium can be very distressing to family and professional caregivers who do not understand it.
 - Although previous care may have been excellent, if the delirium goes misdiagnosed or unmanaged, family members will likely remember a horrible death “in terrible pain” and may worry that their own death will be the same.
6. Respiratory changes, especially apneic spells.
- Changes in a dying patient’s breathing pattern may be indicative of the significant neurological compromise that accompanies the dying process.
 - Breaths may become very shallow and frequent with a diminishing tidal volume.
 - Periods of apnea are the most common changes seen. Cheyne-Stokes or acidotic pattern respirations also may develop.
 - Accessory respiratory muscle use may become prominent.
 - A few, sometimes many, last deep, irregular and infrequent breaths may signal death.
 - Families and professional caregivers frequently find changes in breathing patterns to be one of the most distressing signs of impending death. Many fear that the comatose patient will experience a sense of suffocation. Relating their experience as different than what the patient feels will help to reduce their anxiety and distress.
7. In the very last hours, evident cardiovascular changes including:
- As cardiac output and intravascular volume decrease toward the end of life, there will be evidence of diminished peripheral blood perfusion.
 - tachycardia
 - hypotension,
 - peripheral cooling, peripheral and central cyanosis, and mottling of the skin (livedo reticularis) are normal.
 - venous blood may pool along dependent skin surfaces.
 - Urine output falls as per-fusion of the kidney diminishes. Oliguria or anuria is normal.
 - Parenteral fluids will not reverse this circulatory shutdown.

The Need for Frequent Assessment

- This is a time when there may be rapid changes in a patient’s condition.
- The interdisciplinary care team must be prepared to assess the patient and family frequently.
- The frequent presence of care team members including physicians is comforting for the family.

Rx-Management

There are three phases to management of the last hours.

Phase 1: Preparation

1. This is a time when the focus of care on the family and other caregivers becomes as important as the focus on the patient.
2. The family requires education about the processes accompanying the last hours so that they will have reduced fears and more involvement. The education is best done away from the bedside and done through conversation, backed-up by written information. The education process should cover:
 - The signs and symptoms in the last hours.
 - The role of the family and care providers.
 - The issues of grief.
 - The issues of religious customs, rites, etc.
 - The on-call back-up.
 - Clarifying understood advance directives.
 - What to do when the patient dies and how and when to reach the appropriate care provider.
 - Dealing with fantasies and fears around death and around the adequacy of care in the home.
 - Differing agendas among family members.

The education process often requires repetition in whole or in part on subsequent visits. The approach in educating the family is a psycho-educational one that provides information and support at the same time.

Last Hours Checklist: Education

- ✓ Previous experiences
- ✓ Fears & expectations
- ✓ Changes with dying
- ✓ Food & fluid
- ✓ Pain
- ✓ Being with your loved one
- ✓ Children
- ✓ No 911
- ✓ Pronouncement process

3. What to tell the patient:
 - Patients are often very aware of impending death.
 - They should be encouraged to deal with their own feelings if they can communicate effectively and indicate last wishes/goodbyes.
 - Talk about death if they want to.
 - As time goes on, patients are less & less aware.

- Words need to be chosen carefully:
 - e.g. “Things are changing quickly”, avoiding the word “deteriorating”
- 4. Care provider resources involved in patient care should be contacted about the impending death and arrangements made for urgent responses and increased contact and surveillance.
- 5. Arrangements should be made in advance for alternative administration of necessary medications and supplies and drugs should be ordered.
- 6. The death certification process should be discussed with the family and any care providers.

Phase 2: Symptom Management

1. Positioning

- As the patient becomes weaker, the best position in bed is slightly on the side propped up by pillows along the whole body, particularly supporting the shoulders and trunk areas.
- The head should be minimally elevated except when drinking fluids or eating when full elevation is required.
- Position should be changed every two hours except in the very last hours when position change should be minimized to every 8-12 hours.
- When the patient is showing signs of pooling of secretions, the patient should be nursed on the side with supportive pillows and with the head flat. If there are a lot of secretions, the position can be changed to a semi-prone one.
- A draw sheet should always be used to turn the patient or move them in bed.

2. Skin Care

- If patients are nursed in a position as described above, shearing and friction forces are avoided and therefore the development of new pressure ulcers can usually be avoided.
- Gently cleansing using appropriate cleansers on a regular basis is important for comfort.
- Incontinence should be dealt with quickly and skin cleansed and protected if soiled so that maceration does not occur.
- If there are ulcers present, dressings should be chosen that minimize the number of dressing changes.
- Regular position changes should be limited to every 8-12 hours as long as appropriate and sufficient preventive measures are taken to prevent skin breakdown.
- Massage over reddened areas (early stage 1 ulcers) should be avoided.

3. Mouth Care

- Good oral hygiene should be maintained at all times.
- Dentures if present should be cleaned and regularly moisturized. If the patient is very drowsy, dentures should be removed.

- Regular oral hydration with a mouthwash or by using unflavoured, sponge-tipped swabs.
 - Commercial mouthwashes, lemon glycerin swabs or artificial saliva products should be avoided in favour of a simple solution made up from 1 liter of water, ½ tsp. of salt and 1 tsp. of baking soda.
 - When the patient is taking little orally, mouth care should be done hourly.

4. Pain

- Pain rarely increases at the end of life.
- Assessment more difficult in a patient who is drowsy.
 - Look for “furrowed brow”.
- Moaning is related to delirium, agitation or simple position change or environmental change.
- Remember the pharmacology of opioids especially morphine & its active metabolites.
 - May need to reduce or stop morphine or move to PRN dosing as patient dehydrates.
 - Need excellent pain assessment if moving to PRN dosing.
 - Can continue other opioids such as fentanyl & hydromorphone but observe carefully for toxicity.
 - Remind the family that morphine or other opioids will not hasten death.
- Alternate methods of administration of opioids: (see [Pain Module](#) for details)
 - Sublingual/buccal.
 - Rectal
 - Intermittent parenteral (s.c.)
 - Constant s.c. infusion

5. Nutrition and hydration.

- Concern often expressed by family that patient will suffer if no fluids are administered or that patient will starve to death.
- There is a need for good counseling & education.
- Hydrate s.c. or IV **if there is a reason for doing so:**
 - Reversible condition with considerable life remaining.
 - Special reason.
- Careful attention to keeping moisturized:
 - Lips, nares, conjunctiva
- Swallowing problems:
 - Heralded by decreased intake, coughing on oral feeding, pooling of secretions
 - Need to educate family re: dangers of oral intake at this stage and increased discomfort if aspirates

6. Secretions

- Commonly at the end of life, there is pooling of secretions manifested by gurgling sounds and increased oral secretions.

- Family members often misinterpret this as dyspnea
- Avoid the term “death rattle”
- Pathophysiology:
 - relaxation of oral and pharyngeal muscles
 - pooling of normal secretions because of decreased swallowing
 - occasionally there are excess secretions secondary to pneumonia
- May have moaning with each breath out.
- Positioning is vital. Nurse on the side with supportive pillows and with the head flat. If there are a lot of secretions, the position can be changed to a semi-prone one.
- Avoid suctioning and instead use directed swabbing with sponge-tipped swabs under good lighting using a flashlight.
- Hyoscine/scopolamine.
 - transdermal scopolamine patch
 - s.c hyoscine 0.4-0.6mg s.c. q4-6h using a subcutaneous butterfly needle or special subcutaneous needle left in place under a transparent, semi-permeable membrane dressing

7. Terminal Delirium and Agitation

- May be very common problem but can often be prevented.
- Explain to family & other service providers about the possibility and symptoms.
- Symptoms:
 - Restlessness and moaning
 - Increased confusion
 - Increasing drowsiness
- Treat aggressively to prevent prolonged agitation and increased family anxiety and distress.

Morphine and other opioids should never be given as sedatives. They often increase agitation and delirium.

- First Line:
 - use sublingual lorazepam 1-2mg q1/2-1h p.r.n.
 - make sure buccal membrane moist.
 - expect to use large doses.
- Second Line:
 - Major tranquilizers.
 - loxapine, chlorpromazine, haloperidol.
 - midazolam.

8. Incontinence.

- Urinary catheters may be best.

- Diapers often more difficult for families to use, provide need for increased nursing help and are more intrusive into the process than catheters
- Use diapers only if significant diarrhea or stool incontinence. Otherwise use incontinence pads on the bed.

9. Medications.

- Stop all unnecessary medications.

10. Breathing Patterns and Dyspnea.

- Changes in breathing patterns often mistaken as “he/she is having difficulty breathing”.
- May leads to inappropriate hospitalizations and overuse of oxygen unless family fears are dealt with early and repeatedly.
- Oxygen rarely necessary.
 - May prolong process
 - May need to discontinue oxygen in the very last hours if it is seen as prolonging the dying in patients who are very drowsy or comatose

11. Terminal Sedation

- Heavy sedation at the very end of life may be appropriate.
- Need guidelines and discussions with family members.
- Indications potentially:
 - Severe pain.
 - Severe dyspnea.
 - Severe restlessness.
 - Hemorrhage.
 - Severe family distress.
- Use midazolam, barbiturates, phenothiazines.
 - Constant IV infusion probably best.
 - Can use by intermittent IM/SC injections.

12. Other Issues

- Stop all blood tests or other investigations unless they will significantly change your management and provide more comfort for the patient.

The Last Hours Checklist: Symptom Management

- Positioning
- Skin Care
- Mouth Care
- Pain
- Nutrition and hydration.
- Secretions
- Terminal Delirium and Agitation
- Incontinence
- Medications
- Breathing Patterns and Dyspnea
- Other Issues

Phase 3: At the Time of Death

1. Educate the family beforehand to avoid panic.
2. Advise the family to spend some time with the deceased before calling care providers and respect the sense of peace that accompanies most deaths and their early grief.
3. Begin bereavement counseling, particularly emphasizing early grief reactions and issues around funerals.
4. This is one of the times to say your own good-bye.

Evaluation

1. During this final phase of the illness, the patient and family require frequent monitoring by phone and at least one visit per day.
2. The presence of a physician on-site is often very reassuring for patient and family.
3. Rapid access to the interdisciplinary team must be assured.
4. On-call providers should be informed about the patient and the care plan clarified to keep all care providers in synchrony.

Case Scenario 1

Julian Smithers is a 68-year-old man with non-small cell lung cancer diagnosed 9 months ago. He had radiotherapy to a large hilar mass at the time of diagnosis. He was relatively well for two months when he developed thoracic back pain. This was secondary to bone metastases and spinal cord compression. He received further radiation and morphine for pain control. He is now on 260mg of sustained release morphine every 12 hours with reasonable pain control. Other symptoms include anorexia and cachexia, generalized weakness and mild dyspnea.

You have followed him regularly. He lives with his wife Linda in a 2-bedroom condominium. They have 4 married children – 2 sons and 2 daughters – and 6 grandchildren. One son lives in Texas and the other children live nearby. Julian worked for a small manufacturing firm. Linda who is 60 took early retirement from her civil service job when Julian developed cancer. The local home care program is involved and a nurse visits twice a week.

Linda and Julian have discussed the illness with you on multiple visits. He has indicated that he would like to die at home.

Linda calls you one morning.

“Doctor, I am sorry to bother you. But, you said to call if I had any concerns. I am worried about Julian. The last couple of days, he’s been much sicker. He sleeps almost all the time now. He hardly takes anything – no solid food and only little bits of water. You told me not to worry about that. But, my son, John, you know the one who lives in Texas, called and he thinks he should be on intravenous or something or be sent to hospital so he doesn’t suffer to much.

I was wondering if you could visit us at home today?”

Case Scenario 2

“Doctor, this is John Smithers speaking. Dad died about an hour ago. Peaceful as you said it would be. Could you come over as soon as possible to sign the certificate?”

Detailed Case Scenario

History

Julian Smithers is a 68-year-old man with non-small cell lung cancer diagnosed 9 months ago. He presented with increased dyspnea and substernal chest pain. He saw his family physician. An x-ray showed a large left hilar mass. Bronchoscopy and biopsy showed non-small cell lung cancer. He had radiotherapy to the mass. He was relatively well for two months when he developed thoracic back pain radiating around both sides of his chest. A bone scan showed metastases to T5, 6 and 7. An MRI showed a mass compressing the spinal cord. He received further radiation and morphine for pain control. He is now on 260mg of sustained release morphine every 12 hours with reasonable pain control. He takes immediate release morphine 50mg as breakthrough two or three times a day.

Other symptoms include anorexia and cachexia (with weight loss of 15 kg), generalized weakness and mild dyspnea.

You have been his family physician for 6 years. His only health problem has been mild hypertension treated with an ACE inhibitor and mild hypercholesterolemia treated with lovastatin. He is a non-smoker now but smoked heavily until 10 years ago. He drinks small amounts of alcohol, mainly beer.

You have followed him regularly since his diagnosis. Julian was born in England and immigrated here 42 years ago. He lives with his wife Linda in a 2-bedroom condominium. They have been married 37 years. They have 4 married children. John is the eldest son and he lives in Dallas Texas. His son Chris and daughters Jane and Barbara live nearby. Julian has 6 grandchildren, ages 6 to 13, whom he adores. He has a brother and sister living near London, England.

Julian worked for a small manufacturing firm and retired at age 65 on a company pension. He occupied his retirement with hobbies of gardening and photography. Linda, who is 60, took early retirement from her civil service job when Julian developed cancer. The local home care program is involved and a nurse visits twice a week. The hospital palliative care consultant saw him once when he was admitted for spinal cord compression.

Julian is a Christian (protestant). He has been a regular churchgoer since his retirement. Linda is a Catholic but attends church with Julian.

Julian has no written advance directive but on several occasions he has told his physician that he wants nothing more done should he die.

Physical Examination

He is lying in bed. He is very drowsy but can be woken up. He speaks little but says he is not in pain. His oral membranes are quite dry and his tissue turgor is poor. His blood pressure is 84/56 and he has a regular tachycardia of 132/min. His respiratory rate is 18/minute with occasional briefs periods of apnea. He is afebrile. He has dullness over the upper anterior aspect of his chest posteriorly. He has no myoclonus. He is quite pale. His abdomen is normal.

Linda Smithers looks tired but she seems to be coping so far.

Laboratory Investigations

No tests available on this visit.

Liver function tests in past abnormal and ultrasound showed two large metastases 3 months ago. CBC one month ago showed hemoglobin of 84 with normal white cells and platelets.

Teaching Instructions for Facilitators

Directions for Facilitators:

1. Begin with a recap of outstanding learning issues from the last session. (maximum 1 hr.)
2. Distribute the case scenario. Allow the participants a couple of minutes to read the information or have one of the participants read the scenario.
3. Ask about what learning issues/patient issues there are for the participants. Have them written on the flipchart.
4. The participants need to identify a number of issues including: (approx. 30 minutes)
 - The situation of the last hours of caring.
 - The signs and symptoms of dying.
 - The need to make a rapid assessment.
 - The need for family support.
 - The son in Texas.
 - Advance directives.
5. The participants should move on to request more information about the past illness, the physical examination.

6. Move on to management next. Ask the participants to first think of the issues discussed previously before proceeding to the details.

TIP: An effective teaching intervention is to ask each participant to write an outline of a care plan for this patient. Record the answers on a flipchart as you review them. Review the care plan as written asking participants to note and justify differences and omissions.

7. Hand out Case Scenario 2 and review the issues for this scenario which include:
 - The process of pronouncement of death in your region.
 - The initial grief counseling for the family.
 - The need for some type of bereavement follow-up and review of local/regional resources for this.
 - The issues of care provider grief.

TIP: It may be difficult to draw out physicians about their concerns at this point. You may need to refer back to earlier material about physician attitudes. Sometimes indicating that feeling grief is important will allow open conversation.

8. Review the learning issues that have not been dealt with and assign tasks.