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End of Life Care

Primary Care Paramedicine

Module: 21

Section: 02

End-of-Life Care

- Terminal illness
  - Illness that cannot be cured
  - Considered to be terminally ill when the life expectancy is estimated to be six months or less
  - Though a given patient may properly be considered terminal, this is not a guarantee that the patient will die within six months
- Signs
  - Decreased intake of food and drink
  - Decreased orientation
  - Irregular breathing patterns
  - Bradycardia or tachycardia

End-of-Life Care

- End-of-life care
  - Goal is to provide patients with a meaningful, dignified, and comfortable death.
    - Pain and symptom management
    - Preparation for death
    - Achieving a sense of completion
  - Supportive care
    - Usually the only thing you can do
    - Therapy aimed at comfort
    - Consult medical direction for guidance

End-of-Life Care

DNR order

- If valid, CPR is not indicated or appropriate.
- If questions, start resuscitation while contacting direct medical control.
- Work for comfort

Home versus transport

- Ascertain the family's wishes.
- Allow a family member to accompany the patient.
- Learn local or regional regulations.

Challenges

- Four major challenges to this training

Challenge: Death is Inevitable

- Life is a fatal condition with a 100 % chance of mortality.

- anonymous

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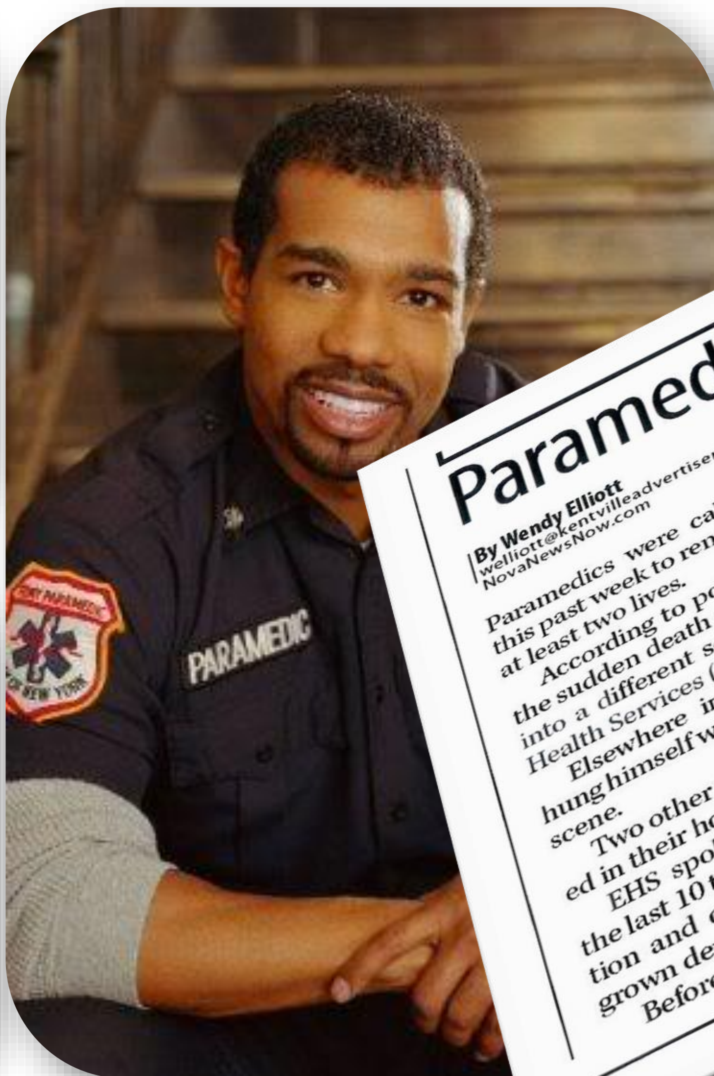
Challenge: Public Perception



Paramedics step up, save lives

By Wendy Elliott
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NovaNewsNow.com

Paramedics were called upon four times this past week to render aid, and they saved at least two lives.

According to police records, a report of the sudden death of an elderly man turned into a different scenario when Emergency Health Services (EHS) staff found a pulse.

Elsewhere in the county, a man who hung himself was revived by paramedics on scene.

Two other elderly people were also treated in their homes.

EHS spokesman Paul Maynard says in the last 10 to 15 years the skill level, dedication and commitment of paramedics has grown demonstrably.

Before 1995, there were over 50 private and public ambulance operations providing emergency transport services in Nova Scotia.

The system had inconsistencies in medical care, levels of staff qualifications and the type and condition of ambulances. Often, the type of care patients received was dependent on where they resided in the province.

Now, Maynard notes, the EHS system in Nova Scotia has become an internationally recognized leader in the provision of pre-hospital care.

He says the government made a good investment and EHS staff has a wide range of tools to assist with emergencies, including trauma and cardiac arrest.

"We have some terrific paramedics here," adds Kings RCMP Cst. Blair MacMurtery.

Challenge: Peer Perception

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Challenge: Education

- Often inadequate
- Recognize the technical aspects of death
- Minimal amount of instruction covering the psychological or social aspects of death
- NOCP?
- Cultural and religious sensitivity, cultural and religious diversity

Topics for Discussion

- The Dying Patient
- Dealing with the Death

End of Life Ethics

- Paramedics treating patients approaching the end of life often face moral, ethical, and legal issues involving:
  - Shared decision making
  - Right to refuse medical treatment
  - Futility

End of Life Ethics

- Beneficence
- Nonmaleficence
- Patient autonomy
- Justice

Shared Decision Making

- Ethical treatment decisions should be shared between physician and patient
  - We act as extensions of this process

Right to Refuse

- Well established in medicine and in law
- Advanced Directives/DNR
  - In situations where there is no DNR and the patient lacks decision-making capacity, courts will allow proxy decision making
- “Substituted Judgment"
  - Many proxies feel uncomfortable in deciding to stop interventions
  - See themselves as deciding between life or death
  - Actual role of the proxy, however, is not to make the decision but to help carry out the patients’ wishes

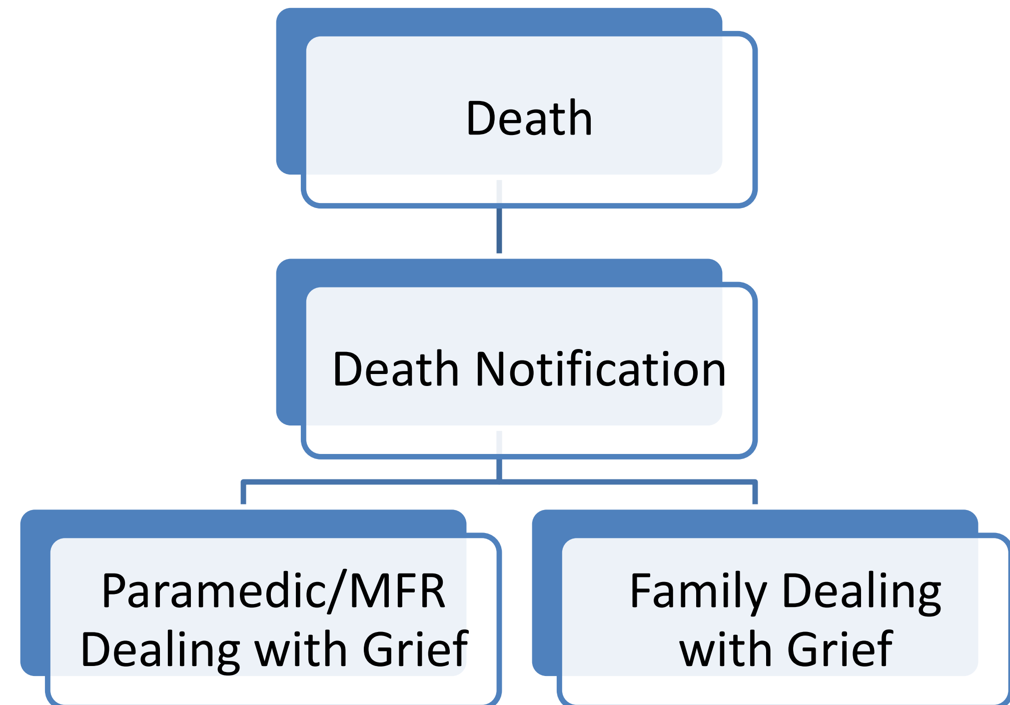
Futility

- No ethical obligation to provide treatment that is futile
- What constitutes futile treatment?

Palliative Care

- Addresses the physical and psychological aspects of end of life. It involves:
  - Pain and other symptom management
  - Social, psychological, cultural, emotional and spiritual support
  - Caregiver support
  - Bereavement support

Dealing with the death


Death
Death Notification
Paramedic/MFR Dealing with Grief
Family Dealing with Grief

The Transition Period: After the family is informed

- Death that occurs outside of the hospital environment takes on four phases:
  - The Acute Phase
    - The death event occurs and a call to 9-1-1 is placed
  - Death Determination Phase
    - Field personnel determine that it would be appropriate not to begin or to cease basic and/or advanced life support measures
  - Investigative Phase
    - Law enforcement and/or the Medical Examiner's Office investigates the incident to ensure that no criminal activity has occurred
  - Removal Phase
    - Removal of the body

Death Notification

Death Notification

- Have a Plan

- Department protocols for out-of-hospital death
- Regional policies
- Do the police come?
- Is there an investigation?
- Who moves the body?
- Where is the morgue or funeral home?

Death Notification

- Have a Plan
- Introduce Yourself

- Rehumanizes the uniform, serving as a small buffer to the information you're about to deliver.
- Validates your information as coming from someone in authority

Death Notification

- Have a Plan
- Introduce Yourself
- Identify Who’s Who
- Figure out the relationship of those present to the deceased.
- When asking, always use the present tense: "Are you the parents/husband/wife of...?"

Death Notification

- Have a Plan
- Introduce Yourself
- Identify Who's Who
- Fire the Warning Shot

- "Preparation statement"
- "We arrived to find your father unconscious. He was not breathing, and there was no pulse, so we immediately began CPR..."

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Death Notification

- Have a Plan
- Introduce Yourself
- Identify Who’s Who
- Fire the Warning Shot
- Get to the Point
- “Core statement.“
- Simple, direct and try to deliver it with compassion
- Using the word died or dead is important

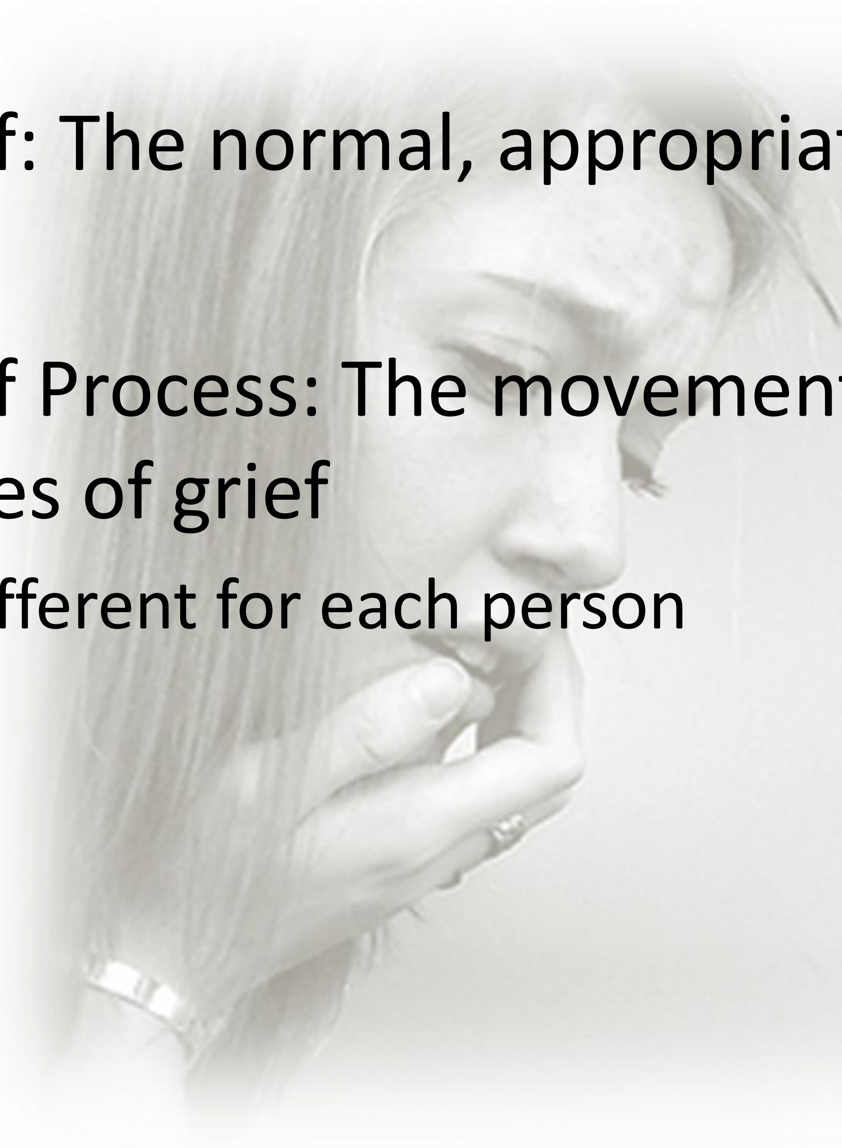
Death Notification

- Have a Plan
- Introduce Yourself
- Identify Who's Who
- Fire the Warning Shot
- Get to the Point
- Express Empathy
- "I'm sorry for your loss"

Death Notification

- Have a Plan
- Introduce Yourself
- Identify Who's Who
- Fire the Warning Shot
- Express Empathy
- Be prepared for the aftermath

THE GRIEF PROCESS: A Normal Process



- Grief: The normal, appropriate emotional response to loss
- Grief Process: The movement of a person through the various stages of grief
  - Different for each person

Grief

- Each person's grief is unique
- No standard timetable
- Not all family members will experience each stage
- EMS personnel may witness one or many reactions during the short time spent with the decedent's family

Kübler-Ross model

- First introduced by Elisabeth Kübler-Ross in her 1969 book, On Death and Dying.
- Five discrete stages
  - Denial
  - Anger
  - Bargaining
  - Depression
  - Acceptance

Denial/Shock

- A conscious or unconscious refusal to accept facts
- A temporary defence mechanism and is perfectly natural
- Shock should also be expected even after a long terminal illness in which the family has been preparing for death

Denial/Shock

- ACTION:
  – Very little of what you say will be remembered by the family. They will remember your kind voice and sense of caring
  – Make eye contact, sit with the family, touch their hand or shoulder if it seems appropriate and acceptable
  – A hug or touch may be more appropriate when departing the scene rather than a gesture of comfort in the middle of the grieving process

Denial/Shock

- Acknowledge what has happened
  - "I'm sorry, your father has died".
- Be honest and give brief, laymen term explanations
  - "His heart stopped and the medication could not get it restarted"
- Give them some time alone for the reality of the situation to set in and for them to collect their thoughts.

Denial/Shock

- Allow family members to hug or hold each other
- Continue to give them small details surrounding the event to help them focus on reality - “He stopped breathing”, “Her injuries were too severe”
- Let them view the body if they want
  - let them make their own decision – there is no right choice

Anger/Emotional Release

- Not uncommon to see intense emotional release by the family
- Crying, screaming, feelings of relief, sadness, helplessness, hopelessness, anger, even laughter
- May be directed to themselves, God, their loved one or even to the EMS crew

Anger/Emotional Release

- ACTION:
  - Allow the family members to express their emotions and encourage them to accept and support each other’s reactions
  - Realize that their anger and emotions are not usually directed at you - do not react back with anger or frustration
  - Instead, try to remain compassionate and supportive. Do not place blame or jump to conclusions

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Anger/Emotional Release

- Avoid “God-talk”
- If Angry/Aggressive
  - Provide safety and security for yourself and the other family members. If someone becomes aggressive or violent, get backup, try to isolate the individual to another area
  - Acknowledge his/her feelings and inform him/her of the consequences of his/her intended actions. Keep a good distance away and don’t threaten or scold

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Bargaining/Guilt

- “I should have done this” or “I should not have done that”
- Bargaining is trying to get them back. Guilt is sometimes real, often imaginary or exaggerated. Death amplifies whatever problems existed in the relationship

Bargaining/Guilt

- ACTION:
  - Allow the family to verbalize their concerns
  - Try to find something positive about their relationship which you can comment upon - “It looks like you have taken very good care of her”
  - Let them know that they participated positively in the death event
  - “You did the right thing by calling 911”. (if appropriate)

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Depression/Fear

- Family members may be afraid to touch the deceased, afraid of sleeping in the same room, afraid of being alone
- Natural to feel sadness and regret, fear, uncertainty, etc

Depression/Fear

- ACTION:
  - Give them permission to view the body. Prepare them by warning them of physical changes that have taken place - the skin may be discolored, a breathing tube may be in place, etc
  - Stay with them until they no longer feel afraid of the deceased
  - Help them to make phone calls to have a neighbor, friend or relative come to stay with them

Acceptance/Reorganization

- The final stage of grief
- May take years for families to reach this stage
  - The family will often go over every little detail leading up to and following the death
- The EMS providers' response to the family experiencing a loss can help them begin their movement through the painful grief process

Grief and Family Needs

- Acute grief is a normal reaction to loss
- In these situations the emotional needs of the family should be of the utmost importance to the health care provider
- The family members often need to be comforted and given privacy
- The loved ones may need to express feelings of rage, anger, despair and sometimes guilt

Grief and Family Needs

- At times, they may need someone to help them in some direction
  - i.e. tentative selection of a funeral home
- The positive role that paramedics take during a situation can help the way that the survivors adjust to their loss
- It is uncomfortable to be in a situation that involves death
- Communication with those that are grieving can be very difficult
- It is important to answer questions that the family may have whenever possible
- It is helpful to explain why you are taking certain actions
  - i.e. calling control, requesting police to attend

Grief and Family Needs

- ACTION:
  - Use compassionate and nonverbal communication (facial expressions, attentive listening and appropriate touch).
  - Remember that each person responds differently to the touch of a stranger, no matter how well intentioned.
  - Take your cues from the grieving person as to whether they need more space or feel comfortable with your approach.

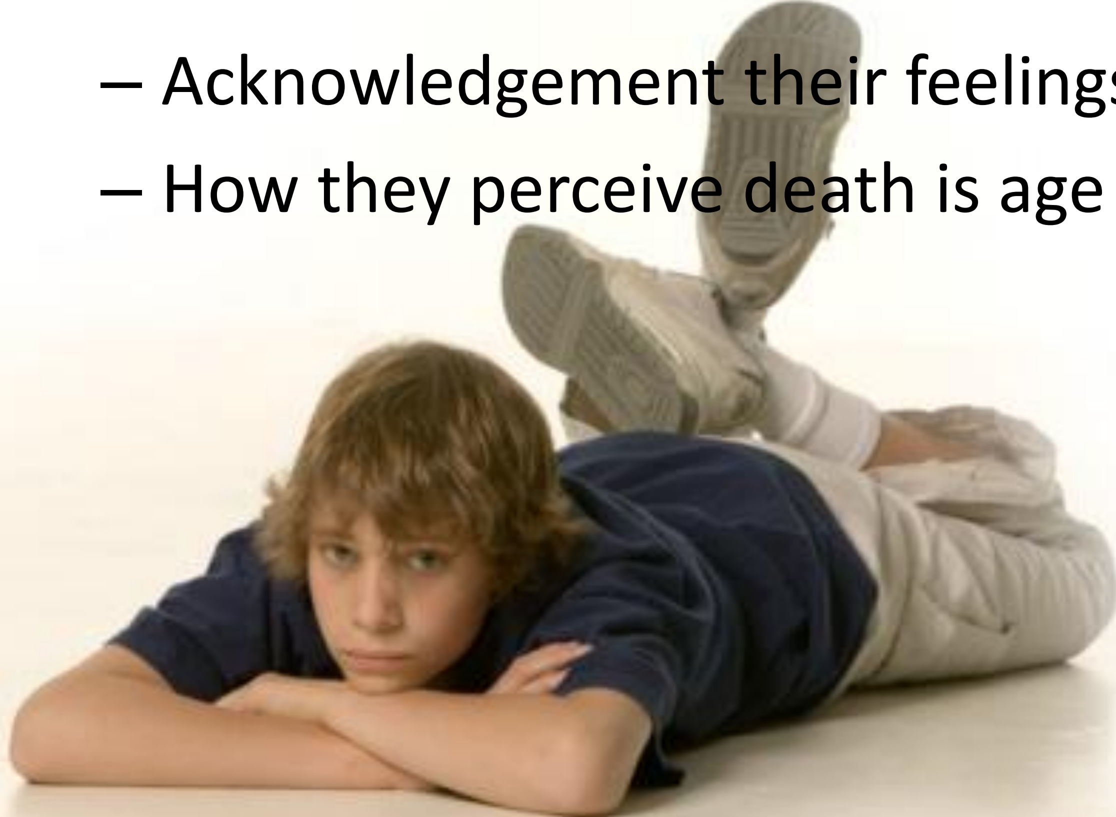
Death of a Child

Death of a Child

- ACTION:
  - Parents may experience more guilt, a prolonged period of numbness and shock and in cases of injury, intense anger at those responsible
  - Allow them the freedom to express their emotions
  - At this time it is best to listen without giving too many comments or explanations
  - Emergency personnel should be sensitive the special needs of children when they are experiencing the death of a loved one
  - It is important to remember the children in the house, especially if the adult family members are involved with their own grief

Children and Death

- ACTION:
  - We are not there to be a counselor
  - Acknowledgement their feelings
  - How they perceive death is age dependant



Children and Death

- PRESCHOOLERS (up to age 6 years)
  - View death as temporary and reversible
  - May view death as punishment for their own thoughts or fulfillment of angry wishes
  - Answers need to be brief, simple and repeated if necessary

Children and Death

- SCHOOL AGE CHILDREN (7-12 years)
  - Death seen as punishment.
  - Still wanting to see death as reversible but beginning to see it as final
  - Specific questions. Desire for complete details.
  - Concerned with how others are responding. What is the right way to respond?

Children and Death

- ADOLESCENTS (12 and older)
  - Understand that death is irreversible
  - Starting to explore personal philosophies of life and death
  - Teenagers may have problems finding coping mechanisms to deal with death depending on their past experiences

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"What do I say and how can I help the families of victims?"

- Always introduce yourself and explain your role in the crisis…
  - The crisis is a confusing time.
  - Simple things like saying your name, explaining who you are, and what you do, will reduce the family's confusion and make your interaction with them more personal.
  - Refer to the deceased by their name when possible, this conveys your respect for their loved one.

"What do I say and how can I help the families of victims?"

- Be there to listen…
  - At this point in time, your priority is to allow the grieving person time to talk
  - Do not rush to return to the field
  - Provide education by answering questions with the truth as you know it
  - Be aware that all questions cannot be answered

"What do I say and how can I help the families of victims?"

- Show your concern, acknowledge their loss, accept expressions of grief and express your own…
- Allow tears
- Understand their anger…
- Expect guilt…
- Be comfortable with silence…

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“What do I say and how can I help the families of victims?”

- Say "I’m sorry"…
- Be careful of the advice you give…
  - Asking “Would you like someone to talk to?” is better than “You need professional counseling.”
- Provide information and offer continued support…
- Remember your posture…
- Check the family’s understanding…

You Should…

- Be there to listen
- Allow expressions of grief, both yours and theirs
- Allow them to share memories of their loved one
- Reassure the bereaved individual that they did all they could
- REMEMBER
  – You can’t take away their pain or bring the individual back

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You Should Not…

- Say “I know how you feel”.
- Say “You ought to…”
- Forget to identify the deceased by name
- Offer platitudes like “Well you can always have another baby”
- Be suspicious or judgmental, such as suggesting the deceased did not have good care

All Patients…

- It is important to remember that many of these calls will be investigated to determine how and why the patient died
- For this reason, it is important to preserve as much evidence as possible while still providing the patient with the best possible care
- Be respectful
- Stay with the family, if possible, until law enforcement arrive to take over the scene
- Remove disposable packing and any litter from the scene. Do not leave it behind for family to dispose of
- You may place a sheet over the deceased to be respectful