# Death of a Child… What next?

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Across cultures, people may differ in what they believe and understand about life and death, what they feel, what elicits those feelings, the perceived implications of those feelings, the ways they express those feelings, the appropriateness of certain feelings, and the techniques for dealing with feelings that cannot be directly expressed…To help effectively, we must overcome our presuppositions and struggle to understand people on their own terms. (Irish, Lundquist, & Nelson, 1993, p. 18)

- Adults die.
- Children die.
- People do die and we may be the ones that determine death, viability, and ultimately be the final ones present as they complete their journey.

On a warm summer day, the mother of a toddler and 6-year old child is briefly distracted by a telephone call that she takes poolside in their backyard.

When she turns around, the 19-month-old is face down in the shallow end of the pool and requires prolonged resuscitative efforts.

A 14-year-old boy is bicycling home from playing in the park and is struck by a car whose driver was apparently intoxicated. The child sustains life-threatening head and thoracic injuries. Despite your best efforts a pulse is never regained.

# Who has dealt with a pediatric death ?

In route?
On scene?
At hospital?

**Who has had formal training in death and dying?**

However core training in death education for EMS is substandard and not consistent.

The minimum required training in this area is lacking.

**Dealing with the topic of death is a complex and difficult challenge.**

Generally, no one calls themselves “death experts” or “really good at dealing with death.”

The mystery of the human heart is such that death is never easy.

But we do talk about our experiences and our feelings surrounding them

Training in grief support is not taught well, if at all, in initial EMS certification programs, but when EMS providers attend grief support training programs, they are more inclined to be willing to confront the family and provide grief support only if they have the training.

**There are training programs like:**

- Death Notification Training by MADD
- Griefstep
- Coping with the Death of a Child, by the AHA

**Others have great online slide presentations for death notification, such as:**

- GRIEVING Death Notification Protocol for interns by Dr. Hobgood,
- Expected Death: What does a paramedic do? by Sunnybrook Osler Center for pre-hospital care,
- Death Notification for Paramedics by Greg Soto

However core training in death education for EMS is substandard and not consistent. The minimum required training in this area is lacking.

**What is death?**

- an end or a beginning
- a private and personal event
- a part of the larger culture
- something to deny or avoid
- something to welcome

**How has dying change over the last 100 years?**

- Death occurs later
- Dying takes longer
- Death often occurs in hospitals
- The main causes of death have changed
- After death….

# Pediatric Death

40,000 children under the age of 14 die each year

20% ( 8,000)  die or are pronounced dead  in the ED setting

Table 1: Leading Causes and Total 5-Year Incidence of Deaths by Age Group, United States, 2004-2008

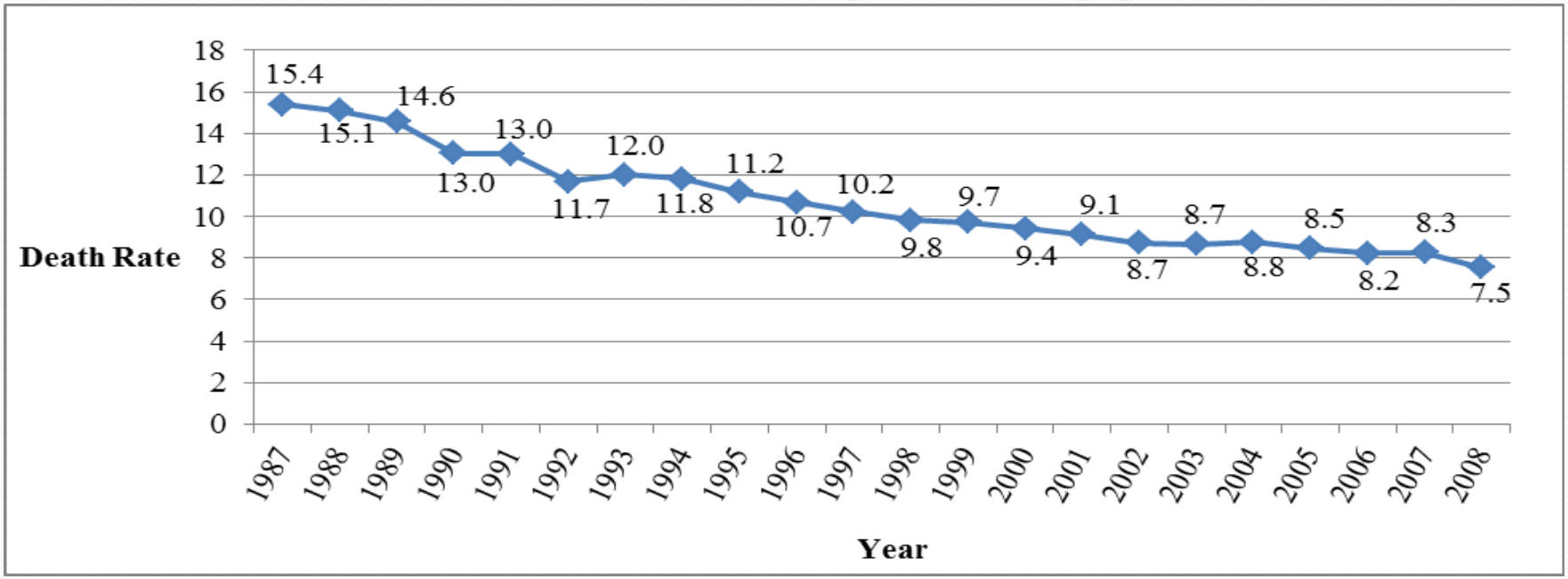
| Age Groups | | | | | |
|---|---|---|---|---|---|
| <1 | 1 - 4 | 5 - 9 | 10 - 14 | 15-19 | 20-24 |
| Congenital Anomalies 28,416 | Unintentional Injury 7,972 | Unintentional Injury 5,042 | Unintentional Injury 6,350 | Unintentional Injury 32,134 | Unintentional Injury 45,283 |
| Short Gestation 23,808 | Congenital Anomalies 2,673 | Malignant Neoplasms 2,407 | Malignant Neoplasms 2,368 | Homicide 10,618 | Homicide 16,476 |
| SIDS 11,605 | Homicide 1,937 | Congenital Anomalies 949 | Suicide 1,164 | Suicide 7,953 | Suicide 13,202 |
| Maternal Pregnancy Comp. 8,708 | Malignant Neoplasms 1,911 | Homicide 638 | Homicide 1,088 | Malignant Neoplasms 3,495 | Malignant Neoplasms 4,891 |
| Unintentional Injury 5,882 | Heart Disease 858 | Heart Disease 486 | Congenital Anomalies 885 | Heart Disease 1,824 | Heart Disease 3,558 |

## Unintentional Injury-Related Death Rates

- Unintentional injuries among children ages 14 and under have drastically decreased from 7,986 in 1987 to 4,643 in 2008

1987 – 2008 Unintentional Injury-Related Deaths Among Children
(United States, Ages 14 and Under, per 100,000 population)

**(United States, Ages 14 and Under, per 100,000 population)[1]**




[1] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS). National Center for Injury Prevention and Control Website. Available from: http://www.cdc.gov/injury/wisqars/index.html. Accessed September 9, 2011.

•From 1987 to 2008 there has been over a **51 percent decrease** in the unintentional injury death rate among children ages 14 years and under. Safe Kids Coalition

| Type of Incident | Number of Deaths in Year 1987 | Number of Deaths in Year 2008 | Percent Decrease/Increase |
|---|---|---|---|
| Motor vehicle crash | 3,261 | 1,350 | ↓59% |
| Pedestrian injury | 1,000 | 269 | ↓73% |
| Bicycle injury | 389 | 84 | ↓78% |
| Drowning | 1,363 | 745 | ↓45% |
| Fire/Burn injury | 1,233 | 366 | ↓70% |
| Suffocation | 690 | 1,294 | ↑88% |
| Falls | 149 | 91 | ↓39% |
| Poisoning | 100 | 94 | ↓6% |

# Many Religions, Many Cultures

- Respect for Ancestors
- Spiritual and Cultural Affirmation

**Near-death experience**

- an episode in which a person comes close to dying but survives and reports having left his or her body and having moved towards a bright, white light while feeling peacefulness and joy

# Bereavement

Normal Grief
Grief and Mourning

**Bereavement**

- the sense of loss following a death

**Grief**

- an individual's emotional response to the death of another

**Mourning**

- the ceremonies and behavior that a religion or culture prescribes for bereaved people

Comedy Inc - The Late Shift - Doctor Delivering News - YouTube.url

<

The importance of being authentic Advice for health care providers - YouTube.url

**Can you remember a time in your life you lost something precious to you?**

- What did you need to hear then?
- What didn’t you need at that time?

Do you consider a failed resuscitation a personal failure to you as a healthcare provider and your abilities?

Have you though about your own death and how your views fit into your work life?

# Predominant Phases of Grief

1. *Traumatic Stress or Shock*
2. *Assimilation*
3. *Acknowledgment and Integration*

**Phases recycle** and blend into one another

Certain feelings predominate in each phase

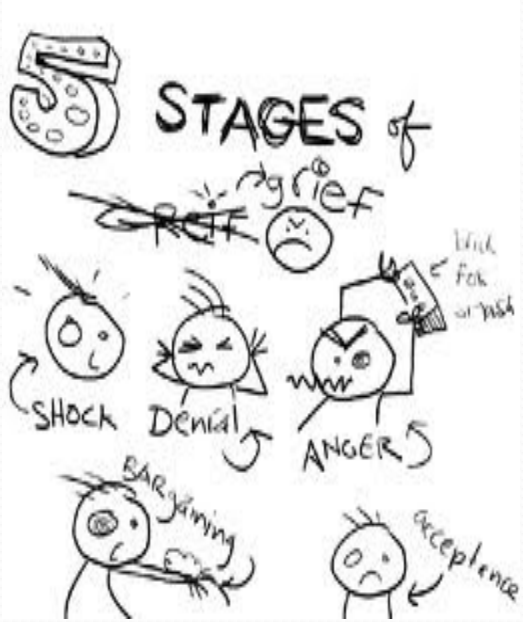
# Phase 1: Traumatic Stress

- Period immediately following diagnosis/event
- Numbness, shock, disturbed sleep, panic, and despair

**Families**

- Make major decisions about treatment and services
- Reports they do not hear what doctors and service providers have said
- Try to understand meaning of diagnosis/event
- May experience relief with diagnosis/event

# Feelings & Behaviors in Initial Phase




- Gather as much information as possible
- Express anger at doctors/providers and diagnosis/event
- Tearful and withdrawn
- Preoccupation with imagined child
- Panic and helplessness
- Focused on immediate needs
- Frightening for siblings

## Phase 2: Assimilation

- Confusion begins to dissipate
- Sharper realization of nature and extent of event
- Family members show highly idiosyncratic, changing responses
- Heavily influenced by personality and contextual factors
- Period when families experience their most intense reactions to loss of hoped-for child

## Feelings in Assimilation Phase

- Hope
- Anxiety and restlessness
- Depression and anxiety
- Guilt
- Anger
- Social Isolation

## Phase 3: Acknowledgment and Integration

- Greater understanding and acknowledgment of event
- Greater integration of event into the family
- Periods of distress are briefer, less intense
- Parents still report “having a bad day”

**Behaviors and Feelings in Integration Phase**

- With help, family members can acknowledge they are feeling better distinguish grief-related stress from other stress

- Acknowledge there is no “getting back to normal.” Families are forever changed.
- Begin to see self as a parent, not just a parent of a child who has died
- Embed learning into daily routine

## FIVE EMOTIONAL STAGES

Denial - or “no not me”
Anger - or “why me?”
Bargaining - or “Yes, but. . .”
Depression - or “It’s me!”
Acceptance - or “It’s part of life.  I have to get my life in order.”

**Elizabeth Kubler- Ross**
Landmark work entitled On Death and Dying.
Identified five emotional stages experienced by dying individuals

# Barriers to Culturally Competent Care

**Institutional Barriers**

- Lack of diversity in health care's leadership and workforce
- Systems of care poorly designed to meet the needs of diverse patient populations
- Poor communication between providers and patients of different racial, ethnic, or cultural backgrounds

**Personal Barriers**

- Experiences present and past
- Coping mechanisms

# Guidelines for Cross-Cultural Nonverbal Communication

- Eye contact – can be sign of disrespect, hostility or rudeness
- Observe family members and members of cultural groups
- Body language and facial expressions – may be interpreted differently
- Ask for clarification of concerns, check for questions, or reword information being presented
- Silence – some comfortable with long silences; some speak immediately
- Listen to conversations between members of the same culture to learn the use of pauses and interruptions
- Silence can have many meanings difficult to assess

## Guidelines cont'd

- Distance – preferred distance is 2-3 feet in U.S.
- Give family members a choice of where to sit
- Stand with room for parents to move closer or farther away
- Touch – norms for how and when to touch
- Touching not common for South Asians and West Indians
- In some Latino cultures, touching conveys lack of respect, especially older people

## Recommendations to Facilitate Communication

- Encourage open dialogue by asking about family relationships, values and beliefs.
- Informally determine fluency of family by asking open-ended question.
- Encourage family to ask questions.
- Ask family questions to check understanding.
- Summarize what the parent says.
- Do not discourage family from talking among themselves in their own language.

## Recommendations to Facilitate Communication

- Work with cultural mediators.
- Learn and use words and forms of greeting.
- Provide information in different forms – oral, written, pictorial, demonstration.
- Rely on the interpreter, observations, instincts, and knowledge to know when to proceed and when to wait.

# The family, the neglected second patient

## Emergency Responder Activity

- Support of Parents
- Use calm directive voice
- Be clear in instructions
- Provide explanations about Tx & transport
- Reassure that there was nothing that they could have done
- Do not be afraid of tears & anger
- Allow parents to accompany infant to hospital if situation permits

In most jurisdictions, the sudden and unexpected death of a child occurring in the field or ED is considered a **medical examiners case requiring an autopsy.**

- legal requirements must be explained to the family.
- It is important to explain to families that the extent of an autopsy is often limited to the relevant injury and that there will be no additional disfiguration that would interfere with an open-casket ceremony.
- Additionally, if it is desired, the medical examiner will often honor requests to restore all organs to the original location

# Environmental Assessment

Observe for:

- Location of infant
- Presence of objects in area infant found
- Unusual conditions
- High room temperature
- Odors
- Anything out of ordinary

## Emergency Responder Activity

- Obtain Hx
- Illicit medical history
- Listen to the parents
- Do not ask judgmental or leading questions
- Use open-ended & non-leading questions
- Had infant been sick

- What happened
- Who found the infant & where
- What did (s)he do
- Had the infant been moved
- What time was infant last seen & by whom
- How was infant that day
- Last feeding

# Anticipated Parental Responses

**Normal responses may include**:

- Denial, shock and disbelief
- Anger, rage and hostility
- Hysteria or withdrawal
- Intense guilt
- Fear, helplessness and confusion
- No visible response
- May or may not accept infants death

# Expected Requests From Parents

- Repetitive questions
- Request to not initiate care
- Request to be alone with infant
- Request to terminate resuscitation efforts
- Requests for cause of death

**Express sympathy and concern, and use phrases that express your feelings and acknowledgement of their loss, such as:**

- “I am sorry for your loss"
- "I see that it is difficult to accept the loss of…"
- "I can't imagine how difficult this is for you"
- “It is normal for you to react as you are"
- "How can I help"

# **Be careful to avoid these phrases**:

•His/her death was for the best

•I know how you feel. My ? died last year

•We all have to deal with loss

•At least he/she died in their sleep

•Religious clichés, such as he/she is in a better place

•You should not feel that way

•Aren't you lucky that at least…

- Snap out of it! Get a hold of your self!

- You must focus on your precious moments

- You at least have another child or ...

Touching is alright, but let the family members express the cue for that.
If they want to hug you, let them but don't initiate it.

## If Parents Interfere With Care

- Show empathy
- Do not become angered or argumentative
- Avoid restraining parent
- Be professional - put yourself in their shoes

## Emergency Responder
## Expectations of Parents Behavior

- Hysterical & tearful responses
- Disbelief that not every parent will initiate CPR
- Disbelief/unable to accept parents decision to not have CPR started
- Cultural differences in mourning and grieving process

# Emergency Personnel Responses

- Withdrawal, avoidance of parents
- Self-doubt
- Anger - wanting to blame someone
- Identification with parents
- Sadness & depression

# Critical Incident Stress (CISM) Management

Stress is an integral part of the profession of Emergency Services

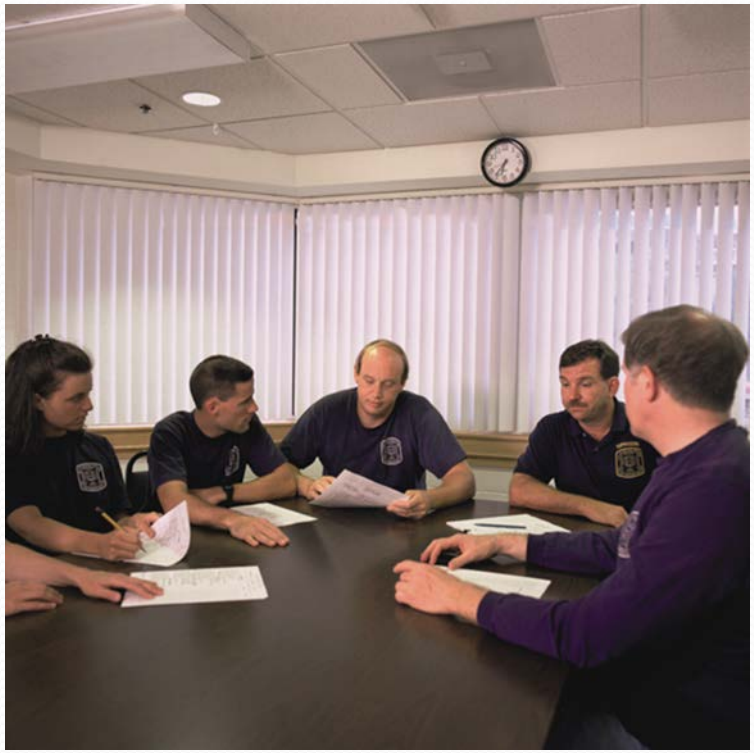
# Signs & Symptoms of CIS

- Anger/irritability
- Physical illness
- Depression
- Recurring dreams
- Intrusive images
- Changes in sleep patterns
- Mood changes/swings
- Withdrawal
- Changes in eating habits
- Inability to concentrate
- Restlessness/agitation
- Loss of emotional control
- Increased alcohol consumption

- Held within 24 to 72 hours of a major incident
- All information is confidential.
- CISD leaders and mental health personnel offer suggestions for overcoming the stress.

# Components of CISM System

- Pre-incident stress education
- On-scene peer support
- Disaster support services
- Defusings



## Components of CISM System

- CISD
- Follow-up services
- Spouse and family support
- Community outreach programs
- Other wellness programs

## Strategies for Decreasing Impact of CIS

- Talk to your peers/ share your feelings
- Exercise and balanced diet
- Avoid OT & plan leisure time
- Write a personal journal
- Obtain personal or religious counseling
- Request dispatch tape reviews
- Request assistance from you local CISM team, post incident

# Diversity of Reactions

bereaved people depend on the customs and attitudes of their culture to guide them though their irrational thoughts and personal grief

# Views of Death in Major Religions

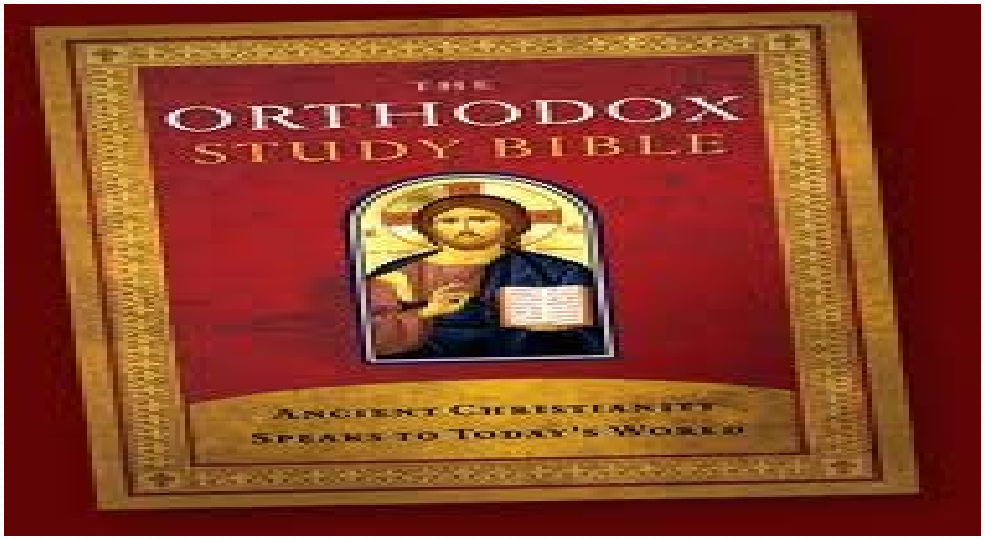
- Buddhism
- Hinduism
- Native American Traditions
- Judaism
- Christianity
- Islam

# Latino Culture

There may be belief that in Latino culture if the person dies in hospital that their spirit is lost rather than dying at home.

## Orthodox Belief

- Body to be treated with respect.
- Family may want to stay with the body until it is removed by the funeral director.
- Burial recommended as soon as possible
- Cremation either prohibited or discouraged



# Buddhism

All rituals at death are aimed at promoting human rebirth in the next life, as well as preventing lower forms of rebirth taking place

- May wish prayers/chanting to take place
- Person's state of mind at moment of death believed to influence rebirth, so they will want to be calm and peaceful.
- believe that this life force, spirit etc. is still present for a time and if the body is moved then a smooth transition to the afterlife cannot take place. Also an outward gushing of emotion is not recommended because it may cause the spirit, or subtle mind to regret dying and be more attached, making letting go and leaving harder.

Unexpected death or death of small child may necessitate special rituals

**Traditionally there is a 3-5 day period where the body is not disturbed following death**

# Hinduism

Prefer to die at home, as close to mother earth as possible (usually on the ground)

- Active euthanasia viewed as destructive
- No custom or restriction on prolongation of life
- Immediately after death priest may pour water into mouth so that the soul may attain liberation .family may wash the body
- Customary for body not to be left alone until cremated
- Autopsy and organ donation acceptable
- Cremation is common on day of death
- Fetus or children under age 2 may be buried; no rituals observed
- Believe the body of the dead must be bathed, massaged in oils, dressed in new clothes, and then cremated before the next sunrise.

Do not touch the body before consulting the family (esp. eldest son) to ask if they wish to perform the last rites as distress may otherwise be caused.

- If no family is available then follow these steps:

- Wearing disposable gloves, close the eyes and straighten the limbs.

- Do not remove jewelry, sacred threads or other religious objects.

- Wrap the body in a plain sheet without any religious emblem. If in any doubt, do not wash the body as the family will wash it as part of the last rites with water from the Ganges, which is collected from the Temple.

- Post mortems are disliked but allowed if legally necessary.
- Adult Hindus are always cremated (although children are buried).

# Native American Indians

Beliefs and practices vary widely from tribe to tribe

- Body is sometimes prepared for burial by family or tribe members
- After person dies, some tribes will not touch deceased person’s clothes or belongings

## Hispanic culture

Death a very important spiritual event

- Relative or member of extended family may help wash the body
- Prayers commonly practiced at bedside of dying patient
- Family time with body before it is taken to morgue

# Chinese

- Family may prefer to bathe body after death
- Special amulets and cloths may be placed on body.
- Bowls of food on table for spirit for 1 year after death

**Gypsy/Roma**

- May ask for religious object in room or favorite foods and personal article of dying person
- May want to have older female relative present
- May want window open to allow patient's spirit to leave
- Moment of death and last words of patient highly significant; relatives will
- Body after death may be source of spiritual danger for relatives until it is embalmed

# Muslims Culture

After death, the body is considered to be the property of Allah .

- DO NOT WASH THE BODY.

- Wear gloves to avoid direct contact with the body. The body should face Mecca (South East) and the head should be turned towards the right shoulder before rigor mortis.

- You may comb hair, straighten limbs, remove equipment and cover the body in a white sheet, but the family will wish to do the washing of the body.

- Post mortems are only permissible if the law requires it.

- The issue of organ donation is confused – the family may agree or not.

- Muslims are always buried within 24 hours of the death

# If a Jewish patient dies

- If the death occurs on the Sabbath (sunset Friday – sunset Saturday) leave the body and contact the family, otherwise proceed as below.

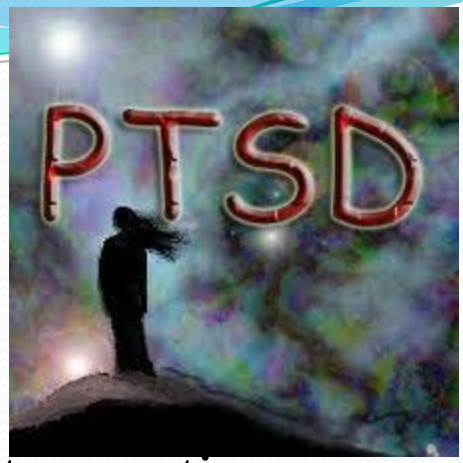
- The eyes should be closed, the body covered and left untouched and candles are lit. Either family members or associates of the same sex will prepare the body for funeral.

- Burial should take place as soon as possible, preferably within 24 hours of death. It is delayed only for the Sabbath .

- If the death has to be notified to the coroner or if the attending doctor is unable to complete the certificate, the family should be informed and asked to contact their undertaker who will liaise with the coroner's office.

# GREEK ORTHODOX

After death, the priest says the first prayer and a candle is lit. This is repeated for 40 days, because it is believed that the soul roams on earth for 40 days, as did Christ
.
The lighting of the candle is symbolic in asking God for forgiveness on behalf of the deceased.




**PTSD (Post Traumatic Stress Disorder)**

- is an anxiety-type disorder occurring after a traumatic experience involving the threat of, or actual, injury or death.

- PTSD was first listed and identified as a psychological disease in 1980 .
- is considered a disease whose victims strive to prevent thoughts, feelings, situations and activities that remind them of some shocking or painful experience that occurred in their past.

**Symptoms can appear immediately following the event, but also may not surface for years**.

- Reliving the Event
- Flashbacks
- Upsetting memories
- Nightmares
- Uncomfortable reactions to similar situations
- Remembering key aspects of the event

**20% of the EMS workforce experienced PTSD.**

The potential for a delay in presentation makes sense when the variety of events that can cause PTSD to occur are considered.

After a stressor has occurred, four broad categories of symptoms may develop reflecting the disease:

- diminished responsiveness
- dissociative states
- aggression changes
- persistent increased arousal

# Some Closing Comments

Our objective as healthcare providers is certainly not to fight death as the enemy.

- That is a fight we will ultimately always lose.
- Our job is to treat the patient.
- Grief is the price you pay for being a dedicated and caring professional.

When I have to tell a family their loved one has just died…I am scared.

Are you scared?

May God grant us the strength when the time comes.

Thank you for all you do!, Every Day!

EMS

Everyday Heroes