

GRATITUDE

- The quality of being thankful. Readiness to show appreciation and to return one's kindness.
- Gratitude is helpful for appreciating our lives, the medical treatment we receive and the love and support we receive from others.
- Gratitude is the antidote to self pity.
- Gratitude increases mood and the determination to tolerate treatment and discomfort.

HUMILITY

- A modest or low view of one's importance.
- Humility reminds us that we will not live forever.
- Humility reminds us we have more challenges to face.
- Humility reminds us not to take others for granted or to take treatment for granted.
- Humility reminds us to resist being self centered.

FOUR BASIC HUMAN EMOTIONS

- FEAR
- SADNESS
- ANGER
- JOY
- Fear leads us to a fight or flight response. When we use flight or avoid what we are afraid of we maintain the fear.
- Sadness is about loss, for cancer patients it involves loss of health and loss of functioning. The thought of death should trigger sadness.

ANGER AND JOY

- We are angry when we are mistreated and/or misunderstood. Clearly cancer does not treat us well and is not understanding.
- Joy is fun and happy, we can feel joy when told we are in remission or cured. We can feel joy for others who are in remission or have been cured.
- We can feel joy when we are well treated by the medical profession. We can feel joy when we are loved and supported. We can feel joy when we give back love and support.

THOUGHTS AND EMOTIONS

- What we think will influence what we feel. When we think about or perceive something to be scary, we will feel fear. When we think we have been mistreated and/or misunderstood we feel anger. When we think about loss, we will feel sad and when we think about something positive and enjoyable we will feel joy.
- In order to have accurate emotions about anything, we have to first think in an accurate manner.

WHAT ABOUT PAIN

- Pain is both physical and emotional
- Pain is subjective, the use of the 1-10 scale
- 90-95% of all pain can be managed well
- But pain can cause emotional distress
- Pain can be acute, intermittent or chronic
- One third of cancer patients in active treatment report pain
- For people in advanced stages of cancer, 60-90% report pain

PAIN MANAGEMENT – TOO MUCH OR TOO LITTLE

- Too much pain medication can lead to addiction, or does it.
- Too little pain medication and patients are uncomfortable
- Some cancer physicians have supported giving cancer patients as much medication as they need.
- State Medical Boards can punish physicians if they document too much pain medication prescriptions
- Today physicians have to use a triplicate form which reports how much pain medication has been prescribed

DELEMMA FOR DOCTORS

- Given concern about addiction, there are now medication regulations
- Often there are more than one source of pain
- 1983 American College of Physicians had guidelines for pain management
- 1986 First guidelines for pain caused by cancer
- 1992 Guidelines for management of cancer pain
- 1992 a study found pain medication management was insufficient
- Many physicians feared using narcotics leading to addiction

SUGGESTED RULES FOR PAIN MANAGEMENT

- Don't limit use of narcotics for fear of addiction
- When pain medications are used for pain, there is less chance of addiction – think of physical addiction and psychological addiction
- Believe the patient when they complain about pain
- Severe pain can last for years prior to death
- No need to delay using narcotics for fear they will be less effective later
- Pain relief is the objective when someone is dying

USE OF SEDATION

- When pain medicines do not alleviate pain well enough, a patient can choose to be sedated.
- Being sedated means the patient is basically unconscious
- Sedation is allowed when it is clear someone is dying

DEATH AND DYING, HISTORY OF THEORIES

- THOUGHTS AND TEACHING ABOUT DEATH AND DYING GO ALL THE WAY BACK TO THE ANCIENT GREEKS AND HEBREWS.
- THE MOST MODERN THEORIES OF DEATH AND DYING ARE BASED ON ANCIENT BELIEFS.
- Philosophers taught to rehearse for death and dying'
- The ancient Hebrews taught people to prepare for dust to return.
- Life is lived with a view towards death. One must engage in dialogue and prayer.
- In 1400 a Catholic Monk wrote *Ars Moriendi* which means the art of dying.
- There are temptations that try to block thoughts of death.
- These include lack of fidelity, despair, impatience, spiritual pride and not wanting to say goodbye.

ARS MORIENDI SUGGESTIONS FOR DEATH

- No need to fight death, better to take care of the soul.
- Those dying should confess regrets and fears to others. The role of others was to reassure God's forgiveness and mercy.
- To die well is to die gladly and wilfully.
- We die best in community, friends and family gather at bedtime to talk of death and to eliminate false hopes of recovery. Prayers are read and the dying are prayed for.
- One does not have to be Pious

BUDDHIST THOUGHTS ABOUT DEATH

- Use meditation
- Awareness
- Think about the afterlife
- Notice one's thoughts
- Do not fight thoughts about death
- No need to study Buddha to die well
- Death is natural
- Death allows us the great opportunity to make the life journey whole

REASONS FOR MODERN DEATH THEORIES

- In 1900 average life expectancy was 50 years.
- Before the rise of modern hospitals, most people died at home.
- In the past it was more likely to see dead bodies outside of the casket
- Today the average life is mid seventies to low eighties.
- Most people die at the hospital, about 70%
- We seldom see dead bodies outside of a wake
- Due to increased life expectancy and gains in medical care, there is less of a need to think about and prepare for death. Younger people deny thoughts about death.

EFFORTS TO PROLONG LIFE

- Advanced medical care can keep very sick patients alive much longer than before.
- CPR prolongs life along with breathing machines, heart assisted machines, aids to excretory system and oxygen
- Advanced medical care is available to terminally ill patients.
- Without a living will or advanced directives, some people are kept alive as long as possible despite poor quality of life.
- Very Important to discuss with others and doctors what are we ask for

FAMOUS CASES WHEN LIFE IS EXTENDED WITHOUT THE PERMISSION OF THE PATIENT

KAREN QUINLAN

NANCY CRUZAN

Both were kept alive though both were unconscious and could not communicate.

Hospitals refused to withdraw life support

Courts became involved

These cases lead to the need for Advanced Directives or Living Wills

WHAT IS SO SCARY ABOUT DEATH

- Loss of control
- What happens
- Ultimate loss of everything
- Fear of losing relationships
- Fear of unresolved conflict
- Most doctors cannot predict accurately how long someone has to live
- With cancer, doctors can determine when someone is terminal
- Many doctors have been overly optimistic about life expectancy

SIGNS OF IMPENDING DEATH

- Decreased eating
- Increased sleeping
- Increased social withdrawal
- Visions
- White Light
- The visions of seeing others and the white light may be physiological, psychological or spiritual
- Visions can be helpful as we do not die alone
- Sometimes an increase in mood and reports of being peaceful

PREPARING FOR DEATH

- Wills
- Advanced Directives – kind of care, who makes decisions, instructions for after death
- Imagine exercise – Where are you, who is with you, what is going on, what sort of care would you want, what fits your beliefs about life and spirituality
- Some people choose to refuse extended life care, others want to live as long as possible

NURSING HOMES AND HOSPICE

- In 1965 Nursing home care was covered by medicare
- Usually nursing homes have been cold and sterile
- Some new strategies have been tried that included dogs and birds and that increased happiness along with giving patients choices
- First modern hospice began in Britain in 1967
- First USA hospice began in 1974
- 1983 Medicare began to cover hospice care
- Hospice patients voluntarily stop all medical treatment to address cancer and/or serious medical concerns

PALLIATIVE CARE

- The goal of palliative care is to provide comfort, not to extend life.
- Non-life threatening conditions are treated
- Pain is treated
- In some cases there can be palliative care along with chemotherapy but not usually.
- The key focus is quality of life
- Famous study at Mass General, cancer patients were assigned to palliative care and non-palliative care while having chemotherapy.
- Those with palliative care outlived those without palliative care.

KUBLER-ROSS THEORY

- Five emotional stages –
- Denial, Anger, Bargaining, Depression and Acceptance
- These emotional stages do not have an automatic order, people can vacillate from one stage to another
- Later on these stages were viewed as resistance to death
- Two additional stages – Finishing Old Business – Discovering truth or transcendence.

OTHER PREPARATIONS FOR DEATH

- Use of a psychedelic drug called Psilocybin. This is a shorter acting psychedelic drug made from mushrooms.
- Dying people can listen to music, do yoga, engage in painting and even dancing
- Guided imagery and prayers
- Telling others I love you, I forgive you and please forgive me
- Yet not all interpersonal issues can be resolved before death

ASSISTED SUICIDE

- Legal in 14 states.
- Not yet legal in Massachusetts
- One must be a resident of the state that allows assisted suicide
- There must be a doctor who certifies the patient will die in 6 months
- There must be a certification that the desire for suicide is not due to depression or non-medical reasons for ending life.

WHAT TO DO BEFORE END OF LIFE

- Remember gratitude
- Remember humility
- Improve relationships with others
- Talk openly about death and answer questions from others
- Nothing wrong with expressing sadness and fear
- Be the person you want to be, not the person you should be

WHAT ARE WE SO AFRAID OF

- Older people are less afraid of death but are afraid of loss, loss of sight and hearing, memory, loss of best friends, family, loss of autonomy and way of life.
- Those who are ill at any age are afraid of suffering. We are afraid to lose mental awareness. We want closer relationships to family. We are afraid of being a burden on others and we are afraid to lose a sense of achievement.
- When we begin the dying process we fear pain, the fear of death and leaving unfinished business.

WHAT TO SAY TO THOSE WHO ARE DYING

- I love you
- I will miss you
- I will comfort you
- Talk about anything you want
- If the dying person is spiritual talk of their beliefs
- Okay to engage in prayer with permission to do so
- Okay to talk of good memories
- Forgive to the extent you can

HOME OR HOSPITAL WHERE TO DIE

- 80% want to die at home
- Others may need more care than a home provides therefore hospitalization
- Concept of Frailty, when people are too frail they need hospital;
- Definition of frailty – loss of 10 pounds in past year, exhaustion, 65 or older, physical weakness, slow walking speed, low physical activity

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