Difficult Decisions

Everything You Want to Know About Dying But Were Afraid to Ask

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HA! YOU CAN'T TOUCH ME HERE! I'M IN THE LIVING ROOM!
DARN! HE'S GOT ME THERE!

Identify Our Fears

- “Do not let your hearts be troubled. Believe in God; believe also in me. In my Father’s house there are many dwelling places. If it were not so, would I have told you that I go to prepare a place for you? And if I go and prepare a place for you, I will come again and will take you to myself, so that where I am, there you may be also.” John 14:1-3
- ‘‘Rejoice in the Lord always; again I will say, Rejoice. Let your gentleness be known to everyone. The Lord is near. Do not be anxious about anything, but in everything by prayer and supplication with thanksgiving let your requests be made known to God. And the peace of God, which surpasses all understanding, will guard your hearts and your minds in Christ Jesus. Philippians 4:4-7

Human Dignity

- We are created in God's image and likeness
- We have stewardship over all material creation
- We are called to neither abuse or squander resources
- We are privileged to work with God through technology and scientific discoveries to conserve, protect and perfect nature in harmony with God's purposes
- Science and faith are both grounded in respect for truth and freedom

Basic Ethical Principles

- Beneficence-to do good
- Nonmaleficence-do not harm
- Autonomy-The ability to make our own decisions
- Justice-Make the best use of the available resources

Euthanasia vs Benemortisia

- Euthanasia- "Easy Death"-an action or omission that of itself or by intention causes death in order to alleviate suffering
- Benemortisia- "To die well" Allowing a Natural Death

- From John Paul II Declaration on Euthanasia:

  Life is a gift of God, and on the other hand death is unavoidable; it is necessary, therefore, that we, without in any way hastening the hour of death, should be able to accept it with full responsibility and dignity.

Proportionate/Disproportionate Means

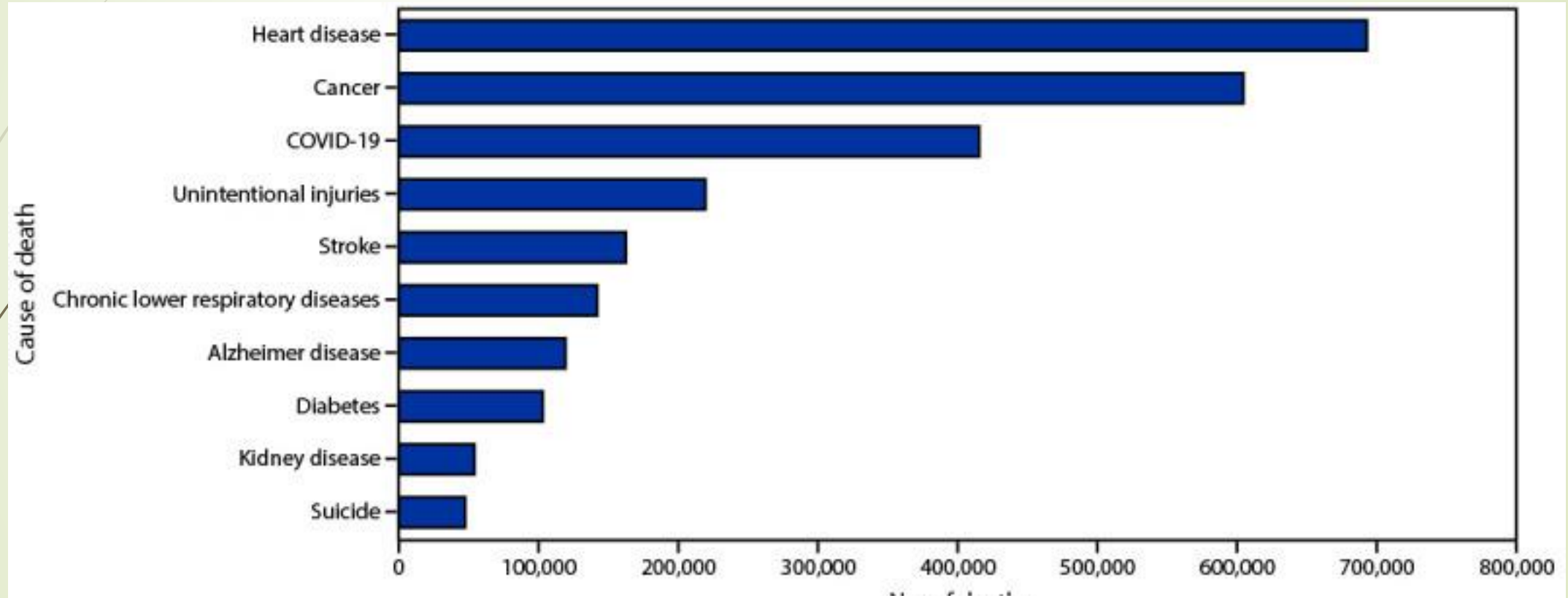
- 56. A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community.
- 57. A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.
- 58. In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the "persistent vegetative state") who can reasonably be expected to live indefinitely if given such care.
- Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be "excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed." For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.

Dying Process Overview

- Immediate/Short Illness
  - Car Accident
  - Fatal Heart Attack or Stroke
  - Homicide/Suicide
  - Drug Overdose

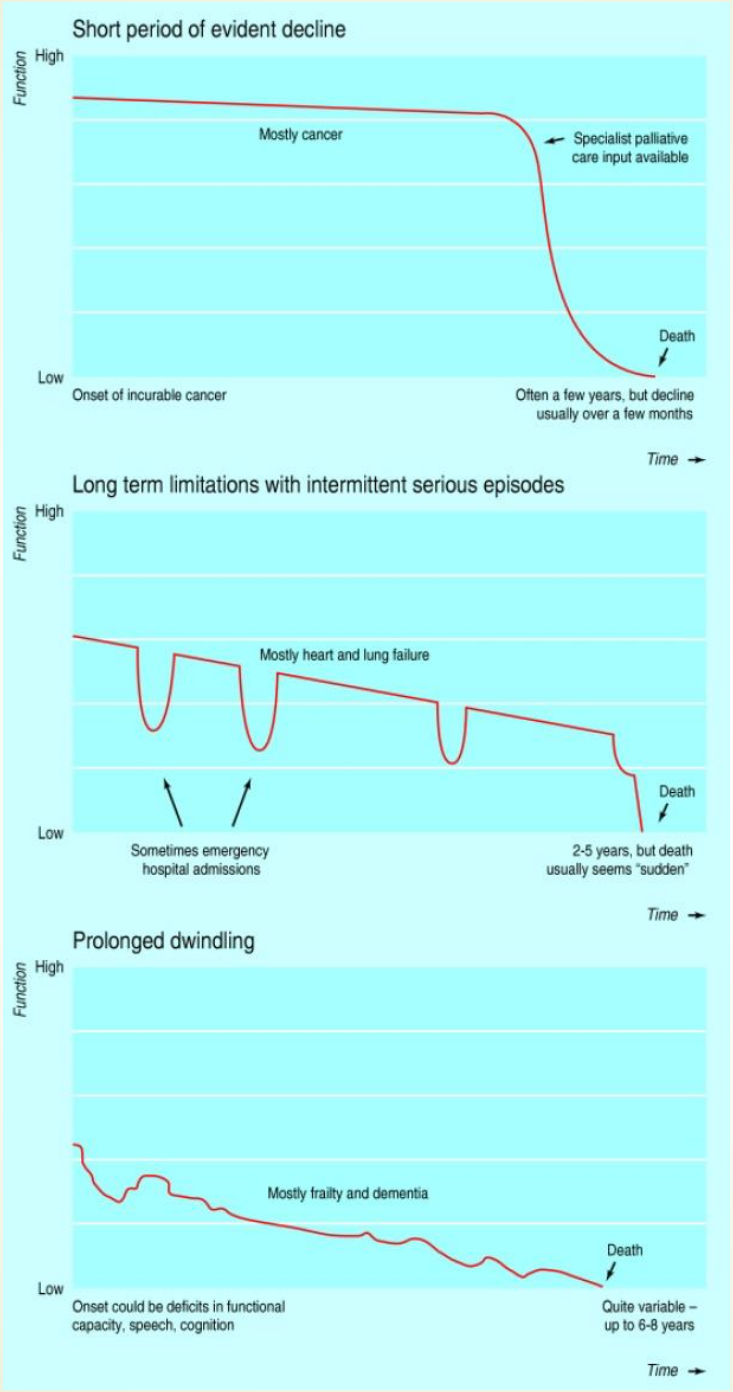
- Medium/Long Term Illness
  - Heart Disease
  - Lung Diseases
  - Cancer
  - Dementia
  - Kidney Disease

Leading Causes of Death 2021



Provisional number of leading underlying causes of death— National Vital Statistics System, United States, 2021

Overall Disease Trajectories



Palliative Performance Scale

Palliative Performance Scale (PPSv2)

Version 2

PPS Level	Ambulation	Activity & Evidence Of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort. Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable normal job/work. Significant disease.	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work. Significant disease.	Occasional assistance necessary	Normal or reduced	Full or confusion
50%	Mainly Sit/lie	Unable to do any work. Extensive disease.	Considerable assistance required	Normal or reduced	Full or confusion
40%	Mainly in bed	Unable to do most activity. Extensive disease.	Mainly assistance	Normal or reduced	Full or Drowsy +/-confusion
30%	Totally Bed Bound	Unable to do any activity. Extensive disease.	Total care	Normal or reduced	Full or Drowsy +/-confusion
20%	Totally Bed Bound	Unable to do any activity. Extensive disease.	Total care	Minimal to sips	Full or Drowsy +/-confusion
10%	Totally Bed Bound	Unable to do any activity. Extensive disease.	Total care	Mouth care only	Drowsy or coma +/-confusion
0%	Death	-	-	-	-

What to Expect-Weeks to Months

Sleeping More

Eating and Drinking Less

Talking Less/Withdrawal

Decreased Socialization

Need Assistance with ADL's

Increased Pain (with some especially cancer)

Vision-Like Experiences

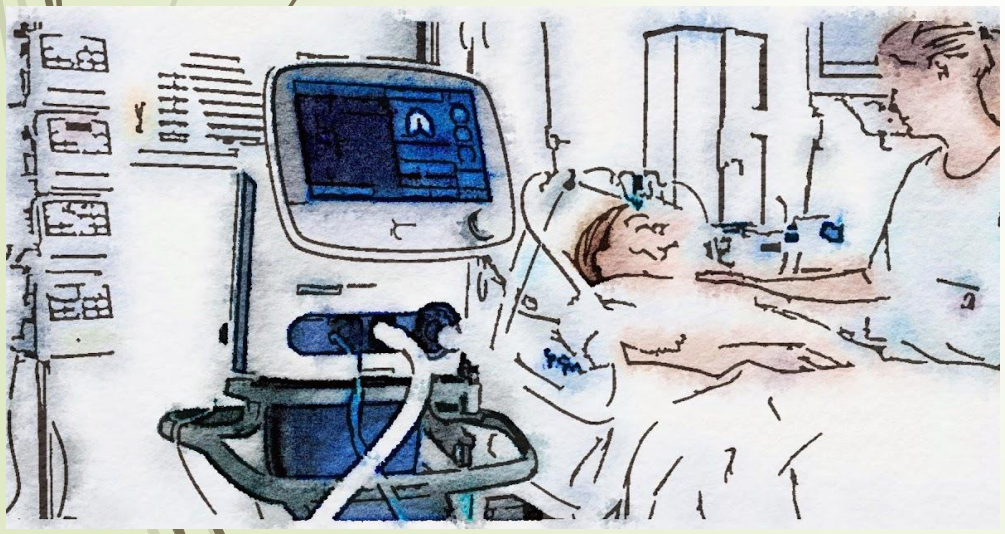
What to Expect-Hours to Days

- Very little to no oral intake “sips and bites”
- Changes to temperature & color of skin
- Incontinence
- Confusion/Disorientation
- Terminal Restlessness
- Decreased urine output
- Minimally responsive or unconscious
- Congestion
- Breathing pattern changes

Camille's Story

Hospital-High Intervention Death

- Yes, I want CPR, what else does that involve?
  - Large bore IV's
  - Ventilator-Breathing tube/surgical tracheostomy
  - Urinary Catheter
  - Constant Blood Pressure/temperature monitoring
  - Multiple physicians/large care team
  - Noise of high acuity unit
  - Support from Social Workers, Palliative Care Team, Chaplain
  - Limited Visiting Hours for family and friends
  - Necessary for Organ Donation



What are your chances of surviving CPR if you are already in the hospital?

What are your chances of surviving CPR if you are already in the hospital?

- In Hospital cardiac arrest initial survival 24.8%
  - Survival to discharge-12.6%
  - Survival to discharge with no complications-0%
  - Common complications:
    - Neurological decline 48%
    - Functional status decline-84%

Peberdy MA, Kaye W, Ornato JP, et al. Cardiopulmonary resuscitation of adults in the hospital: A report of 14,720 cardiac arrests from the National Registry of Cardiopulmonary Resuscitation. Resuscitation. 2003; 58 297-308.

Low Medical Intervention Death (Allowing Natural Death to Occur)

- Typically at home or in Residential Care Facility
- Support from Hospice Team by phone 24/7
- Oral meds given by family to control symptoms
- Family determines visiting hours
- Family responsible for daily care of person-including cleaning/turning

Some Practical Terms

- Ventilator
- Pacemaker/AICD
- Dialysis
- Feeding Tube
- DNR/MOLST
- Do Not Resuscitate (DNR) does NOT mean Do Not Treat
- When to “withdraw care” or switch from curative care to “comfort care”

Pain Management at End of Life

- Ethical & Religious Directives
- 61.Patients should be kept as free of pain as possible so that they may die comfortably with dignity, and in the place where they wish to die. Since a person has the right to prepare for his or her death while fully conscious, he or she should not be deprived of consciousness without a compelling reason. Medicines capable of alleviating or suppressing pain may be given to a dying person, even if this therapy may indirectly shorten the person's life so long as the intent is not to hasten death. Patients experiencing suffering that cannot be alleviated should be helped to appreciate the Christian understanding of redemptive suffering.

Pain Assessment IN Advanced Dementia (PAINAD)

	0	1	2	Score
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-stokes respirations	
Negative Vocalization	None	Occasional moan or groan. Low level speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
Body Language	Relaxed	Tense. Distressed pacing. Fidgeting	Rigid. Fists clenched, Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
TOTAL*				

* Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

Warden, V., Hurley, A. & Volicer. L. (2003). Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. JAMDA, 4(1), 9 -15

Common Misconceptions

- Myth: If I give her pain medicine, she will die.
- Fact: Opioids given in a a person-specific dose related to their prior use and overall kidney/liver function will not shorten the life span, but may actually increase it as there is less stress on the heart/lungs due to the stress of pain or shortness of breath

- Myth: If she takes pain medicine, she will fall asleep and not wake back up
- Fact: Most people acclimate to the new dose of medication within 24-48 hours and the side effect of drowsiness lessens. People at the end of life naturally have less energy due to their disease process and sleep more regardless of medication.

Common Misconceptions

- Myth: If she takes narcotics, she will get addicted to them
- Fact: When opioids are used for pain control, all of the medication is used by the opioid receptors within the nerves. It is when those pain receptors do not need to be blocked that people get the sensation of being "high". Withholding pain medication until someone is in a lot of pain actually requires higher doses of medication to get the person comfortable again.
- In 1992, Schug et al reported only one case of addiction among 550 cancer patients who experienced pain and were treated with morphine for a total of 22,525 treatment days

Medications Used at the End of Life

- Morphine/Hydromorphone-Pain, Shortness of Breath
- Lorazepam-Anxiety, Nausea, Seizures
- Haloperidol-Agitation, Restlessness, Nausea
- Steroids-Pain/Shortness of Breath
- Laxatives/Suppository-Constipation
- Atropine-Congestion

Transplants/Organ Donation

- Living Donor:
  - Bone Marrow
  - Kidney
  - Partial Liver
  - Umbilical Cord Blood

Deceased Donor

- The organs will not be removed until medical death has been determined.
- No conflict of Interest
- Organ Donor on Driver's License

What does the Church Say?

Ethical & Religious Directives

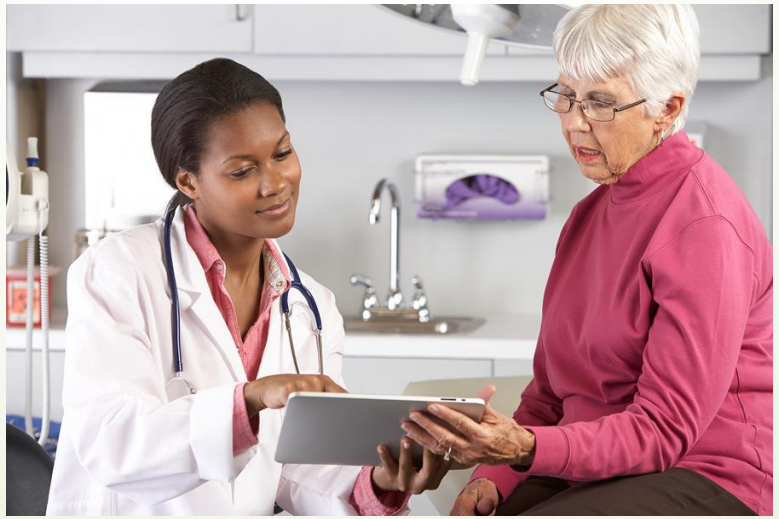
- 63. Catholic health care institutions should encourage and provide the means whereby those who wish to do so may arrange for the donation of their organs and bodily tissue, for ethically legitimate purposes, so that they may be used for donation and research after death.
- 64. Such organs should not be removed until it has been medically determined that the patient has died. In order to prevent any conflict of interest, the physician who determines death should not be a member of the transplant team.

Anyone need a break?

What Do You Want the End of Your Life to Look Like?

Questions for Your Health Care Team

- What is my overall prognosis?
- What would this disease process look like?
- If I have this treatment/surgery, what would the recovery look like, how long would it take?
- What are the most common complications?
- What is my prognosis if I do not have this surgery/treatment?



Levels of Care

- Acute Care (Hospital)
  - Medical/Surgical
  - IMC-Intermediate Care Unit
  - ICU-Intensive Care Unit
- Home Care Services
  - Nursing Aide/Companion
  - Skilled Nursing
  - Home Physical and Occupational Therapy
- Living Facilities
  - Independent Living
  - Assisted Living
  - Memory Care
  - Skilled Nursing Facility

HOSPICE VS. PALLIATIVE CARE

What Are The Differences?

	HOSPICE	PALLIATIVE
DIAGNOSIS	Terminal	Serious, but not necessarily terminal
TIMEFRAME	Final 6 months of life	Anytime
TREATMENT	Pain management (no curative treatment)	Pain management + curative treatment
WHERE	Anywhere you call home	Anywhere you call home
TEAM	Doctors, nurses, social workers, chaplains, dietitians	Doctors, nurses, social workers, chaplains, dietitians

HospiceWise

Brought to you by HospiceWise.org

How Do We Choose?

- Use Hospital & Palliative Care Social Workers
- www.aplaceformom.com
- Talk with others who have made these decisions
- There is no one "right" answer that meets everyone's needs
- Make the best decision for you or your loved one with the information you have at the time
- If facility, choose one close to home, takes insurance, visit regularly at different times throughout the day/evening

Caregiver Support

Be compassionate to yourself and other family members throughout this process

Everyone copes differently-it is not right or wrong

Anticipatory Grief (person and caregivers)

Information Dissemination
www.carecalendar.org
www.caringbridge.org
www.lotsahelpinghands.org

It is OK to ask for help!

What's the least helpful thing you heard when grieving?

Understanding Grief

Grief is an expected and natural reaction to a loss

There is no timeline for this process

Expressions of grief will look different for everyone

Grief can manifest itself in many and unexpected ways

Complicated grief, Compounded grief

How to Support Someone Who is Grieving

- Show up-especially after most others have disappeared
- Know this isn't a problem to fix…there are no right words that will take away the pain of grief
- Be a Listening Ear
- Offer concrete help-groceries, child care, lawn care, go with them to a grandchild's play, to mass
- Call or text just to check in, especially evening and weekends
- Invite them for a meal, or bring a meal to them

What NOT To Do

- Don't offer unsolicited advice
- Don't offer trite phrases or platitudes (When in doubt, silence is better)
- Don't ask prying questions about what happened
- Don't try to "cheer them up"

Redemptive Suffering

- Psalm 22:14-15

  I am poured out like water,
  and all my bones are out of joint;
  my heart is like wax;
  it is melted within my breast;
  my mouth is dried up like a potsherd,
  and my tongue sticks to my jaws;
  you lay me in the dust of death.

Hope in Christ