Stewardship of Life

The Final Journey
Church of the Nativity
HH Hospice Family Care
Inpatient Facility
Redstone Village
HH Hospice Family Care
Inpatient Facility
Redstone Village
Church of the Nativity

HH Hospice Family Care Inpatient Facility
Redstone Village
Stewardship of Life
The Final Journey

The Rev’d Deacon Robert Serio, MD
Stewardship of Life

- Week 1 - Healthy Living
- Week 2 - What Slows Us Down
- Week 3 - Legal Stuff
- Week 4 - The Final Journey
Stewardship of Life
The Final Journey

- Living Wills
- Lesson for Surrogates
- Good Death
- Funeral Arrangements
- Bereavement
- Bucket List
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- Living Will
  - Terminally Ill
    - 2 doctors agree that condition cannot be cured and death will result without the use of artificial life sustaining procedure
  - Life Sustaining Treatments
    - Medications (antibiotics, blood pressure support, rhythm drugs)
    - Machines (ventilators, dialysis, cardiac pumps)
    - Procedures (surgery)
    - Does not include pain or comfort meds
  - Nutrition and hydration
    - IV fluids
    - Tube feedings
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• Living Will
  ◦ Permanently unconscious
    • 2 doctors agree that you can no longer think or feel anything, knowingly move or be aware of being alive
    • Condition will last indefinitely with no hope of improvement
    • Life sustaining treatments and food and hydration
  ◦ Other Directives
    • Use antibiotics but not other meds
    • Surgery for comfort but not for curative intent
    • Palliative radiation
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- Health Care Proxy
  - Makes medical decisions if you are too sick to speak for yourself
  - Should discuss wishes with the Proxy
    - Assumption that we are responsible to each other
  - Physician needs contact information
  - First and second choice
    - ? Medical knowledge
    - Put patients needs and desires before their own
    - Family trusts
    - Good leadership and decision making skills
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• Personal Self Assessment Scale
  ◦ Living wills written in nonspecific future tense
  ◦ DNR/AND written for the here and now
  ◦ PSAS gives advance directives on daily quality of life through end of life stages.
  ◦ Adapted from Palliative Performance scale used for functional assessment and prognosis
  ◦ Should be included as part of the “living Will”
Personal Self-Assessment Scale (PSAS)

<table>
<thead>
<tr>
<th>PSAS level</th>
<th>MOBILITY</th>
<th>ACTIVITY INDEPENDENCE</th>
<th>EVIDENCE OF DISEASE</th>
<th>SELF-CARE</th>
<th>INTAKE</th>
<th>CONSCIOUSNESS SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSAS 100%</td>
<td>Full</td>
<td>Normal activity is work</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>PSAS 50%</td>
<td>Full</td>
<td>Normal activity is work</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>PSAS 25%</td>
<td>Reduced</td>
<td>Unable normal activity &amp; work</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Norm or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>PSAS 10%</td>
<td>Reduced</td>
<td>Unable to do any activity</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Norm or reduced</td>
<td>Reduced</td>
</tr>
<tr>
<td>PSAS 5%</td>
<td>Reduced</td>
<td>Unable to do most activity</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Norm or reduced</td>
<td>Reduced</td>
</tr>
<tr>
<td>PSAS 2%</td>
<td>Reduced</td>
<td>Unable to do any activity</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Norm or reduced</td>
<td>Reduced</td>
</tr>
<tr>
<td>PSAS 1%</td>
<td>Reduced</td>
<td>Unable to do any activity</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Norm or reduced</td>
<td>Reduced</td>
</tr>
<tr>
<td>PSAS 0%</td>
<td>Reduced</td>
<td>Unable to do any activity</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Norm or reduced</td>
<td>Reduced</td>
</tr>
</tbody>
</table>

**INSTRUCTIONS:**

1. Each PSAS level is explained by checking the rows from left to right.
2. After reviewing PSAS levels, move to the green columns under the title "Personal Preferences.
3. Each green "Personal Preference" column identifies key medical decisions that you may choose in advance to have activated when you reach a certain PSAS level:

   - DM = Do not Resuscitate order (no CPR, electrical shocks, breathing tubes)
   - No PAH = No artificial nutrition (example, feeding tubes)
   - No MAV = No IV for artificial hydration
   - Other = Any medical treatment(s) that you may elect not to have (blood transfusions, dialysis, hospitalization for anything other than comfort care, etc.). Details of the "Other" category must be listed in the space provided beneath the columns.
4. For each medical decision that you wish to make in advance for yourself, place an "X" in each column (example, DMV in the row matching the PSAS level of your choice (example, PSAS level 50%).
5. Sign and date this document. Place it in your living will. Give a copy to your health care provider, your surrogate medical decision maker and any family or friends whom you wish to have a copy. Take a copy with you whenever you go to see a doctor. The form is available for download from www.OKtoDie.com.

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Signed by: ____________________________ Date: __________________
Witness/Notary: ______________________ Date: __________________

*It is strongly advised that this be reviewed at least every 6 months, or upon any major change in your medical condition in order to keep it current with your preferences. When renewing or if changes are needed, then use a new form with a new date of completion, and destroy the older one.*
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• Lessons for Surrogates
  ◦ Understand loved ones wishes in detail
  ◦ Have copies of Living Will, HC POA, POA if available
  ◦ Make decisions you believe your loved one would make for themselves
  ◦ Fierro’s 4 Rs
    • Reflect—think back and image when your loved one was able to make his/her own decisions
    • Reconstruct Preferences
      ◦ Favorite things, colors, hobbies, food, dislikes
    • Reconstruct Values
      ◦ Opinions, beliefs, values, how did they choose to live their life
    • Review medical options and decide
      ◦ Imagine your loved one standing next to you hearing the diagnosis and options
        What would he/she want us to do

It's OK to Die, Monica Williams-Murphy MD, Kristian Murphy, MKN LLC, 2011
OKtoDie.com
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The Final Journey

• Terminology
  ◦ DNR/AND-Do Not Resuscitate/Allow Natural Death
    • No chest compressions, electrical shock, ventilator, cardiac drugs
    • Frequently more complex order
      ◦ i.e. DNR/AND but allow shock or cardiac drugs
      ◦ Many times the patient is already on the ventilator
  ◦ DNI-Do Not Intubate
    • Usually means do all resuscitative measures but do not put on the ventilator
    • Will result in death if unable to sustain respiration
  ◦ Freeze Care
    • Continue all current supportive measures (ventilator, drugs, etc) but do not add any new therapy (i.e. dialysis, cardiac shock, stronger drugs
  ◦ Withdraw Care
    • Stop all support except comfort measures
    • Sometimes a problem for health care providers
Physician Orders for Life Sustaining Treatment (POLST)
- Directions for healthcare givers/EMS personnel
- Valid only in certain states (Alabama has approved)
- Must be signed by 2 physicians (attending or primary and consultant)
- Order to withhold resuscitative measures in event of cardiac arrest “in the field”.
- Includes orders to provide comfort measures and alleviate pain and support the family, friends and others present.
- Must be signed by the patient, closest relative, HC POA or court appointed guardian
- Copy on bright color paper (orange) and kept in prominent place (ie refrigerator)
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• A Good Death
  ◦ Sense of Control
  ◦ Honor wishes of the dying person
  ◦ Closure-goodbye
  ◦ Affirm unique personal qualities
  ◦ Trust in healthcare provider
  ◦ Recognition and acceptance of impending death
  ◦ Honor beliefs and values
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• Making peace with death
  ◦ Denial
  ◦ Anger
  ◦ Bargaining
  ◦ Depression
  ◦ Acceptance

It's OK to Die, Monica Williams-Murphy MD, Kristian Murphy, MKN LLC, 2011
OKtoDie.com
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• Death Plan
  ◦ Release unresolved anger
  ◦ Commit to living the rest of your life to the fullest
  ◦ Focus on beauty, love, joy
  ◦ Write or plan your final chapter
    • Only in death is your life complete
    • Ending story may herald a time of potential growth for survivors
    • Funeral/memorial service a time to recite and summarize story
    • Does not need to wait until funeral
      ◦ Letters to loved ones
      ◦ Collections of stories about your family, growing up, interesting events
      ◦ What advise would you give to others
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• Things that need to be said
  ◦ To those dying
  ◦ By those dying
  ◦ May need a surrogate

I’m sorry
I forgive you
Thank you
I love you
It’s OK to die
Goodbye
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The Final Journey

• Location of death
  ◦ Many times we do not have the choice
  ◦ Hospice can facilitate location but may not be practical
    • Inadequate home care
    • Estrangement
    • Sudden deterioration (ER)
    • Feelings of survivors
  ◦ Try to make a sacred space
    • Prayers, rites, music, family, friends
    • Objects with special meaning
      • Candles, crucifix, beads, paintings
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- Organ Donation
  - Limited, all
  - Age may limit
  - Does not delay funeral arrangement
  - Does not disfigure body
  - No cost to family for organ donation
  - Need to discuss with family so they are aware of your wishes

- ALABAMAORGANCENTER.ORG
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The Final Journey

- Funeral Arrangements
  - Preplanned
  - Cremation needs to be specified
  - Cost vary
    - Embalming
    - Coffin
    - Vault
    - Cemetery
<table>
<thead>
<tr>
<th>Item</th>
<th>2014*</th>
<th>2004*</th>
<th>% Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nondeclinable basic services fee</td>
<td>$2,000</td>
<td>$1,460</td>
<td>37.0%</td>
</tr>
<tr>
<td>Removal/transfer of remains to funeral home</td>
<td>$310</td>
<td>$195</td>
<td>59.0%</td>
</tr>
<tr>
<td>Embalming</td>
<td>$695</td>
<td>$498</td>
<td>39.6%</td>
</tr>
<tr>
<td>Other preparation of the body</td>
<td>$250</td>
<td>$174</td>
<td>42.9%</td>
</tr>
<tr>
<td>Use of facilities/staff for viewing</td>
<td>$420</td>
<td>$339</td>
<td>23.9%</td>
</tr>
<tr>
<td>Use of facilities/staff for funeral ceremony</td>
<td>$495</td>
<td>$395</td>
<td>25.3%</td>
</tr>
<tr>
<td>Hearse</td>
<td>$318</td>
<td>$225</td>
<td>41.1%</td>
</tr>
<tr>
<td>Service car/van</td>
<td>$143</td>
<td>$100</td>
<td>42.5%</td>
</tr>
<tr>
<td>Basic memorial printed package</td>
<td>$155</td>
<td>$95</td>
<td>63.2%</td>
</tr>
<tr>
<td>Metal casket</td>
<td>$2,395</td>
<td>$2,100</td>
<td>14.0%</td>
</tr>
<tr>
<td>Median Cost of a Funeral With Viewing and Burial</td>
<td>$7,181</td>
<td>$5,582</td>
<td>28.6%</td>
</tr>
<tr>
<td>Vault</td>
<td>$1,327</td>
<td>$998</td>
<td>33.0%</td>
</tr>
<tr>
<td>Total with vault</td>
<td>$8,508</td>
<td>$6,580</td>
<td>29.3%</td>
</tr>
</tbody>
</table>

2004 prices have not been adjusted for inflation.
* Median Price – The amount at which half of the figures fall below and half are above.
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</tr>
<tr>
<td>Basic memorial printed package</td>
<td>$155</td>
</tr>
<tr>
<td>Cremation fee (if firm uses a third-party)**</td>
<td>$330</td>
</tr>
<tr>
<td>Cremation casket</td>
<td>$1,000</td>
</tr>
<tr>
<td>Urn</td>
<td>$280</td>
</tr>
</tbody>
</table>

**Median Cost of a Funeral with Viewing and Cremation**

$6,078

* Median Price – The amount at which half of the figures fall below and half are above.
**65% of respondents use a third-party crematory (i.e., the funeral home does not own a crematory)
• Church of the Nativity

• Funeral Planning Guide
  ◦ Directives from the BCP
    • Arrangements for the funeral should be made in consultation with the Minister of the Congregation.
    • The liturgy for the dead is an Easter Vigil. It finds its meaning in the resurrection. Vestments are white in celebration.
    • The coffin is closed before the service and remains closed thereafter. It is covered by a pall or other suitable covering.
    • It is desirable that the lesson from the Old Testament and Epistle be read by lay persons.
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The Final Journey

• Bucket Lists
  ◦ Health Care Issues, Opinions and Options
    • Second opinion, time course, hospice, location of death
  ◦ Required End of Life Paperwork
    • Advance directives, POA, POLST, estate plan, will, Nativity Trust
  ◦ Communication with family
    • Tell family about condition, discuss wishes, private discussions, things to say, support, legacy
    • Unresolved issues with family/friends, letters to write
  ◦ Insurance and financial
    • Where are the policies, who is the beneficiaries
    • Who will pay the bills

It's OK to Die, Monica Williams-Murphy MD, Kristian Murphy, MKN LLC, 2011
OKtoDie.com
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• Bucket List
  ◦ Personal effects
    • Valuables
    • Photos
    • Unfinished projects
    • Pets
  ◦ Funeral plans
    • Obituary
    • Burial plot
    • Memorial instead of flowers

It's OK to Die, Monica Williams-Murphy MD, Kristian Murphy, MKN LLC, 2011
OKtoDie.com
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The Final Journey

• While you still have time
  ◦ Places to see
  ◦ Things to do
  ◦ Family/friends to spend time with
  ◦ Projects to start/finish
  ◦ Personal history
  ◦ List of regrets to resolve
  ◦ Ways to enhance spirituality
  ◦ Sports, hobbies, activities to try (skydiving)
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• Bereavement
  ◦ Humans are biologically motivated to form secure close relationships with a few other people (attachment)
  ◦ Secure attachment includes a partner that is available, sensitive and responsive in providing a “safe haven” during periods of stress and a secure base from which one can explore the world, learn new things and take chances.
  ◦ Close adult relationships are reciprocal so that each person provides and receives this support.
  ◦ Loved ones contribute to one’s sense of belonging and sense of identity.
  ◦ Caregiving is part of this love relationship
  ◦ Bereavement creates a state of acute attachment insecurity.

Shear, et al, Grief and Bereavement in Adults, UpToDate.com, July 2017
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- Bereavement
  - Reaction to the loss of someone close
  - Grief is the natural response to bereavement (thoughts, feelings, behaviors and physiologic reactions).
  - The pattern and intensity of grief varies over time as the bereaved individual adapts to the loss.
  - Adaptation is influenced by cultural and religious rituals and is unique to each person and each loss.
  - Acute grief can be intense and disruptive but is eventually integrated.

Shear, et al, Grief and Bereavement in Adults, UpToDate.com, July 2017
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• Complicated Grief
  ◦ Grief that is prolonged, intense and disabling.
    • Troubling thoughts, dysfunctional behaviors, dysregulated emotions and/or serious psychological problems impede the adaption to the loss

• Mourning
  ◦ The process of adapting to a loss and integrating grief.
  ◦ Entails accepting the finality and consequences of the loss, revising the internalized relationship to the deceased and re-envisioning the future such that there is a possibility of happiness in the world without the deceased.
    ◦ Redefine goals and plans
    ◦ May require new responsibilities and roles.

Shear, et al, Grief and Bereavement in Adults, UpToDate.com, July 2017
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• Type of loss
  ◦ Loss of a child
    • Usually most intense grief
    • Parents blame themselves for failure to protect child
    • May feel they have lose their own future by losing child
    • May have survivor guilt to make them feel they should not enjoy their own lives
  ◦ Loss of spouse
    • Difficult especially if relationship positive and rewarding
    • May feel guilt about letting partner down or failure as a caregiver
  ◦ Loss of parent
    • Factors include age, complicating illness and relationship
  ◦ Acute/Chronic/Terminal Illness

Shear, et al, Grief and Bereavement in Adults, UpToDate.com, July 2017
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- Majority of deaths occur as the natural consequence of the aging process
- Most persons adapt to the loss with support from family and friends
- Bereavement different from other life stress in that a period of intense emotional pain and disruption of daily activities is expected and socially sanctioned.

Shear, et al, Grief and Bereavement in Adults, UpToDate.com, July 2017
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- Medical problems associated with grief
  - Increased risk of mortality
    - 21x greater risk for MI within 24 hours of death of a significant person
    - Overall numbers are low
  - Increase in somatic symptoms
    - Worsening of established chronic health problems
    - Poor nutrition and weight loss
    - Poor sleep
    - Increased alcohol consumption
  - Psychological issues
    - Anxiety/depression
    - PTSD
    - Substance abuse
    - Suicide

Shear, et al, Grief and Bereavement in Adults, UpToDate.com, July 2017
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• Role of healthcare provider
  ◦ Many clinicians lack expertise in discussing prognosis and are uncomfortable in dealing with emotional response
  ◦ Most clinicians overestimate the patient’s and families understanding of the disease process and prognosis. Many are overly optimistic in presenting facts.
  ◦ Individuals with low level of preparation for their spouse’s/family members death are at increased risk for anxiety, emotional problems and sleep disorders.
  ◦ When clinicians are insensitive or avoid their dying patients, caregivers are at risk for complicated grief and other mental health problems.

Shear, et al, Grief and Bereavement in Adults, UpToDate.com, July 2017
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• Management of Grief
  ◦ Support
    • Family, friends, church congregation, clergy
    • Physician
  ◦ Maintain regular schedule
    • Eating, sleeping, exercise
    • Invitations for lunch/dinner or coffee to talk
  ◦ Counselling
  ◦ Medication
When there are no words to say:

“I’m sorry he/she is gone.”
“I cannot imagine what you are going through.”
“What are you remembering about __________ today?”
“It was an honor to know him/her.”
“We will miss him/her.”
“How has his/her death affected you/changed your life?”

Talk about your relationship with the deceased. Mention his/her name frequently.
Stewardship of Life

- Week 1 - Healthy Living
- Week 2 - What Slows Us Down
- Week 3 - Legal Stuff
- Week 4 - The Final Journey
Our Lord Jesus Christ be with us to defend us, within us to keep us, before us to lead us, beside us to guard us, and above us to bless us. Amen.
QUESTIONS?

References:

It's OK to Die, Monica Williams-Murphy MD, Kristian Murphy, MKN LLC, 2011
OKtoDie.com
Shear, et al, Grief and Bereavement in Adults, UpToDate.com, July 2017