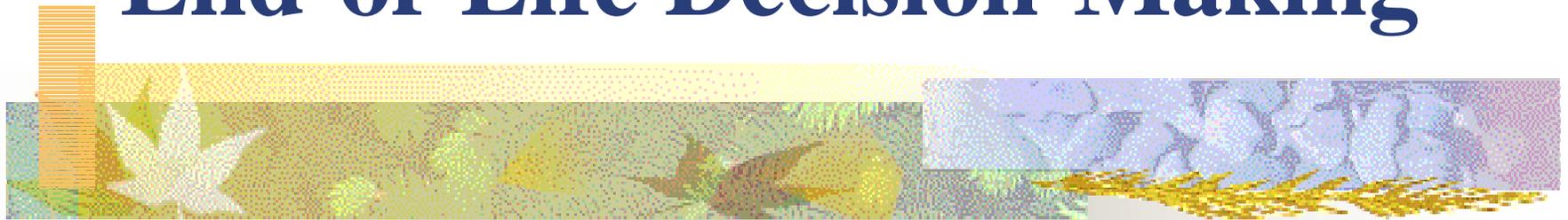
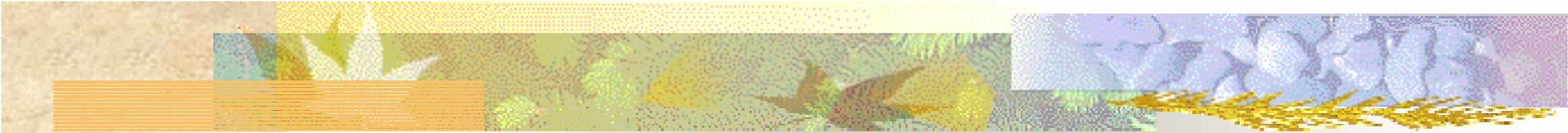


End-of-Life Decision-Making



Ian Anderson Continuing Education Program
in End-of-Life Care



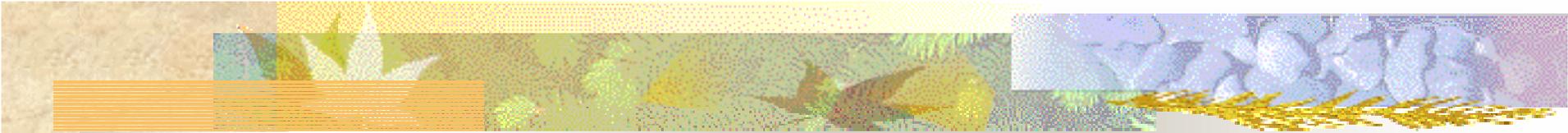
Sense of Self and Decision-Making

- Our sense of self is shaped by our families, past experiences, our sense of health, society and culture
- This sense of self influences all our experiences
- Our choices and decisions are a reflection of our sense of self, our goals, values and beliefs



Decision-Making and Illness

- Reactions to diagnosis, decisions and influencing factors are NOT solely based on medical facts, risks and benefits
- The way facts are weighed, interpreted and the importance placed on different risks are deeply personal
- Difficult to predict decisions of another



Health Care Providers and Decision-Making

- Duty to help with decision-making
- Patients want to know how treatments will improve their quality of life and achieve goals
- Explore what they want, fear, hope for and value
- Place risks and benefits into context and likelihood of treatment achieving desired outcomes



Objectives

- Construct a care plan based on patient's and families' goals to enhance sense of control at the EOL
- Discuss the role of advance care planning and provide guidance in constructing advanced directives
- Demonstrate skill in assessing capacity
- Demonstrate skill in decision-making with capable and incapable patients/substitute decision-makers



Objectives (2)

- List the elements of consent
- Discuss the use of specific treatments
 - 1) Life support
 - 2) DNR orders
 - 3) Antibiotics
 - 4) Artificial Nutrition
- Discuss withdrawing/withholding of treatment at EOL



Objectives (3)

- Discuss how personal experiences of death and dying and experiences of caring for dying patients influence attitudes towards treatments at EOL
- List factors that lead to requests for euthanasia and assisted suicide
- Reflect on the importance of caregiver stress and ability to care for dying patients



Quality EOL Care — Patient's Perspectives

- Adequate pain and symptom management
- Avoid inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burden
- Strengthening relationships with loved ones

**Singer P.A., Martin D.K., Kelner M., Quality End-of-Life Care:
Patient's Perspectives, *JAMA* 1999 281(2) 163-168**



How do I know if I am providing quality EOL care?

- Am I adequately treating pain and other symptoms?
- Am I helping patients and families set goals?
- Am I inappropriately prolonging dying?
- Am I helping patients and families achieve a sense of control, relieving burdens and strengthening relationships?
- Am I involving a multidisciplinary team and working with this team to provide the best quality EOL care?

Singer P.A., Martin D.K., Kelner M., Quality End-of-Life Care: Patient's Perspectives, *JAMA* 1999 281(2) 163-168



Advance Care Planning

- Process of making decisions about future medical care with the help of health care providers, family and loved ones
- Discuss diagnosis, prognosis, expected course of illness, treatment alternatives, risks and benefits
- In context of patient's goals, expectations, values, beliefs and fears
- First step is to assess patient's capacity



Capacity

- Capacity = ability to
 - 1) understand the nature of the decision
 - 2) appreciate the consequences of a decision or lack of decision
- Assessed in relation to particular decisions
- May change over time: drugs, illness, emotions, lack of sleep, delirium can result in **TEMPORARY** incapacity



To Understand & to Appreciate

- **Understand:** Grasp and retain information relevant to the decision at hand
- **Appreciate:** Grasp how a given treatment will affect him/her personally



Does the Patient Understand?

1. Has the relevant information been provided in language they can understand (including fluency)?
2. Has the person been educated about his/her illness, treatment alternatives AND been given the opportunity to ask questions?
3. Does the person understand that he/she has a choice, what each alternative involves, its risks and benefits?
4. Can the person remember the information long enough to reach a decision?
5. Can he/she remember the choices he/she has made and be consistent over time?



Does the Patient Appreciate?

1. Does the person understand how a given treatment, its risks and benefits and the available alternatives will affect him/her personally?
2. How did he/she arrive at this decision? Was it reasoned? i.e., based in reality and consistent with his/her values, beliefs, culture?



Incapacity

- Respect for value and dignity of others means must be protected from making decisions that would:
 1. result in harm
 2. be different from decisions they would have made if capable



Capacity Assessments

- **General impressions:** biased
- **Cognitive:** mini-mental exam – do not assess judgment or reasoning
- **Specific:** to the decision at hand, e.g. ACE (Aid to Capacity Assessment)
- Performed by MDs, bioethicists, SW, RNs, psychiatrists/psychologists
- If challenged, decisions can be reviewed by Consent and Capacity Boards if challenged



EOL Decision-Making

- People need time to reflect on goals, values and beliefs
- *EOL decision-making is a process not a one time event*
- May need several meetings
- Multidisciplinary team involvement in these meetings helps to convey information, discuss alternatives, provide emotional and psychological support



EOL Decision-Making — Multidisciplinary Team Involvement

Important to involve the team:

1. Avoids confusion about treatment goals
2. Avoids “Mixed Messages”: confusion about alternatives, risks & benefits
3. Allows the team to provide emotional and psychological support
4. Improves the quality of care



EOL Decision-Making with Capable Patients

1. Start the meeting
2. State the purpose
3. What do they know or understand about their illness?
4. What questions do they have?
5. Describe the expected and likely course of illness
6. **AVOID** giving false hope



EOL Decision-Making with Capable Patients

7. Take a values history: What are they expecting, hoping for? What is important to them? What do they fear?
8. Listen, show empathy, respond to emotions
9. Work as a team to develop realistic goals
10. Plan and F/U: What do we have to decide now? In the future? Who will be consulted?
11. Document: discussed, decided, outstanding
12. Review and revise if and when needed



Phrases to Avoid

- “It doesn’t look good”

- ➔ Vague! Tell them what is happening: it may be less frightening

- “Do you want us to do everything?”

- “We will refrain from extraordinary, heroic, aggressive measures”

- ➔ Not helpful in informing and implies substandard care



Subsequent Discussions as Illness Progresses

- What to expect the future course of illness will be
- What the final days will be like
- What to expect of the dying process
- How pain and symptom will be treated
- Where they would like to die



EOL Decision-Making when the Patient is Incapable

- When incapable, risk loss of dignity and respect for intrinsic value as persons
- Substitute decision-makers and written advance directives attempt to ensure wishes, values are expressed



Substitute Decision-Makers (SDM)

- Appointed in Durable Power of Attorney for Health Care

OR

- Hierarchical list under provincial legislation

OR

- Public Guardian and Trustee



Role of SDM

- Help decide *what the patient would have wanted if still able to tell the health care team* NOT what the SDM would want
- May be difficult to predict what patient's decision would have been
- Open discussion with SDM should be encouraged in anticipation of future incapacity
- If cannot predict what patient would have wanted, best interest standard can be used



Families/Loved Ones as SDM

- Difficult role: stress of
 - 1) seeing loved one seriously ill AND
 - 2) understanding nature of illness, treatment options and
 - 3) making “best” decision

- Anxiety and guilt common



How can I help the family member acting as SDM?

- Acknowledge and respect the difficulty of their role
- Care for their well being
- Offer emotional and psychological support
- Show them you consider them part of the team



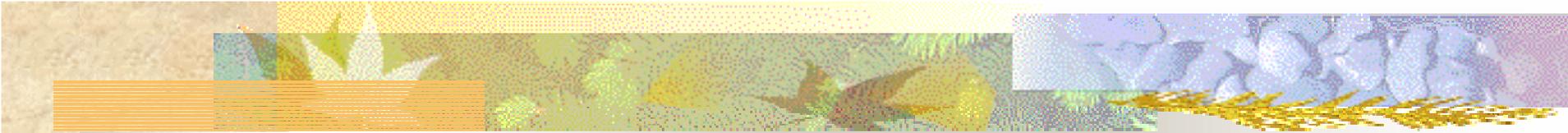
EOL Decision-Making with SDMs

1. Start the meeting
2. State the purpose of the meeting
3. What do they know or understand about their illness?
4. What questions do they have?
5. Describe the expected and likely course of illness
6. Explore the patient's previously expressed wishes, values and beliefs



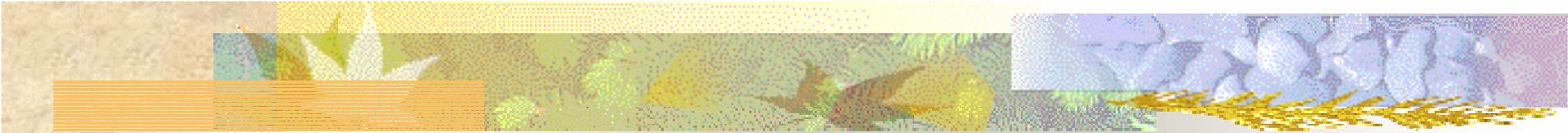
EOL Decision-Making with SDMs

7. Acknowledge the difficulties of the substitute's situation
8. Normalize the experience
9. Empathize
10. Place the decision-making in a teamwork context
11. What are the physicians' recommendations in view of the patient's previously expressed values, goals and beliefs?



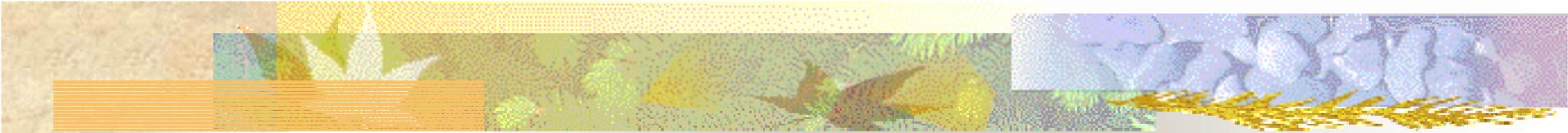
Avoid Saying

- “What do you want us to do?”
- “Do you think we should pull the plug/
stop aggressive treatment/stop everything?”
- “Its time we withdraw care”



Intra-Family Conflict

- Results from emotional, psychological stress and fatigue
- Pre-existing conflicts may re-open and may seem as though they occurred only yesterday



What should I do if there is intra-family conflict?

- Focus them on goal: not to resolve these old conflicts but to make decisions that respect patient's wishes, values and goals
- Ask them the reasoning behind the decisions they arrived at
- Ask them who had most contact with the patient, who knew him/her the best
- Remember the role of other team members in helping with conflict



Health Care Providers and Conflict with SDMs

If doubt SDM is fulfilling their role:

- Check if he/she **understands** the patient's situation
- Check if he/she **appreciates** the implications of illness, treatments, risks, benefits for the patient
- Get a second opinion about your interpretation of illness and treatment options
- Consult Bioethicist, Mediator
- Consult the courts if not resolvable



Written Advance Directives/Living Wills

- Describes what treatments would be desired in event of life-threatening illness
- Most useful if discussed in advance with MDs and family or loved ones in context of notions of quality of life, goals, values, beliefs and fears



Written Advance Directives/Living Wills Problems

- Wishes change
- In context of given illness, previously desired treatments would not be of benefit or chance of benefit would be so small that desire to undergo Rx is questioned
- Imprecise, vague language leading to misinterpretation
- Failure to anticipate given illness/decision



Consent

- Patients have the right to make decisions about their medical treatments even at the EOL
- Consent must be obtained from capable patients or SDMs if incapable
- Place all decisions in context of:
 - 1) how they will affect remaining QOL
 - 2) whether they will prolong life
 - 3) whether benefits > burdens
 - 4) whether they will allow achievement of remaining goals
 - 5) the larger picture of death and dying



Three Elements of Consent

- Capacity
- Disclosure
- Voluntariness



Disclosure

- Provide relevant information AND ensure understanding
- Reasonable person standard = Ethical and legal standard
- Cultural differences in who information is disclosed to and how
- Ethical obligation to provide honest picture of expected course, treatment options, risks/benefits



What is reasonable person standard?

- Prognosis and consequence of no treatment or delay in treatment
- Accessible alternatives, risks, benefits and likelihood of achieving desired goals
- Side effects, the likelihood of occurrence, expected discomforts
- Limits of knowledge/uncertainty/research
- Information that patient asks for
- Physician's opinions on best treatment in context of patient's values history

Dickens B. M., *The Doctrine of "Informed Consent": Informed Choice in Medical Care, Justice Beyond Orwell* Abella R.S. & Rothman M.L. eds. 1985 p. 243-263



Voluntariness

- Free of undue influence
- **External** sources
 - 1) force
 - 2) coercion
 - 3) manipulation
- **Internal** sources
 - 1) limited alternatives
 - 2) uncontrolled pain & other symptoms
 - 3) emotional & psychological



Specific Rx — Life Support

- In the last stages of illness, not undertaken
- Short life expectancy DOES NOT mean excluded from ICU
- Most people have either no conception of life support or serious misconceptions
- Need to explain:
 - 1) ICU/life support
 - 2) what such interventions can or cannot do in context of values history
- Consult intensivist/visit ICU when uncertain



Time-Limited Trials

- If understand the potential benefits of ICU but fear
 1. the discomforts involved
 2. living dependent on a machine
 3. living in a persistent vegetative state
 4. OR if benefits uncertain

- Allow achievement of specific goals or sense that “everything” was tried



Time-Limited Trials — End-Points

- At the patient's request
 - Anticipated benefits are not seen
 - If burdens > benefits
 - After a predetermined time
-
- Reassure the patient that they will be kept comfortable as life support is withdrawn



Is there a role for life-sustaining treatment at the EOL?

- In what context will it be needed?
- What does the patient know and understand about ICU/ventilatory/inotropic support?
- Clarify misconceptions
- What will be accomplished in context of values history?
- What will life support not accomplish?
- Explain the role of a trial of therapy
- If a trial is undertaken what are the end-points?
- What would the physician recommend?

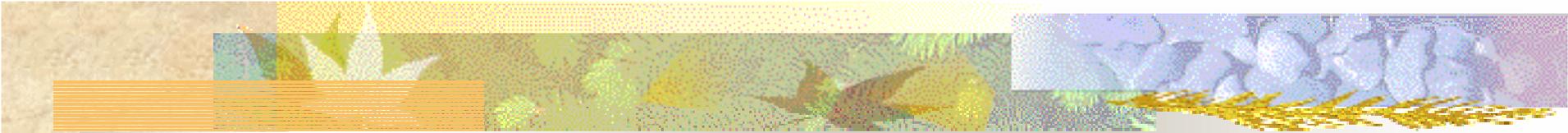


DNR Orders

- Explain cardiopulmonary arrest, what is involved in resuscitation, risks/benefits AND subsequent need for life-support
- Realistic/honest picture
- Misconceptions about what is involved and likelihood of success
- Narrow in scope:
 1. say nothing about ICU admission → discuss separately
 2. do not imply patient wants limits imposed on other treatments

DNR Orders

- Help patients and families make sensible choices: no sense to have CPR but not intubation
- Do not expect immediate decision
- **Joint Statement on Resuscitative Interventions 1995**
- Slow codes are always inappropriate
- Do not have to offer resuscitation if chances of success are nonexistent **BUT** inform patient that it will not be offered
 - ➔ allows patient to seek second opinion



Artificial Nutrition

- May not achieve goals of improving energy, nutrition and hydration
- Decreased appetite and dehydration = normal part of dying
- Good mouth care may be more important
- Physicians need to explain what is involved in NG, G/J-tube insertion and care, risks, benefits in context of patients' goals, values, beliefs



Withholding/Withdrawing Treatment

- Withholding/Withdrawing can be done:
 1. At the patient's request
 2. Desired benefits will not be achieved
 3. Anticipated benefits not achieved
 4. Burdens > benefits
 5. Change in goals or priorities
 6. Change in health
 7. Change in health care setting

- Ethically and legally equivalent



Withholding/Withdrawing Treatment

Things to Explain....

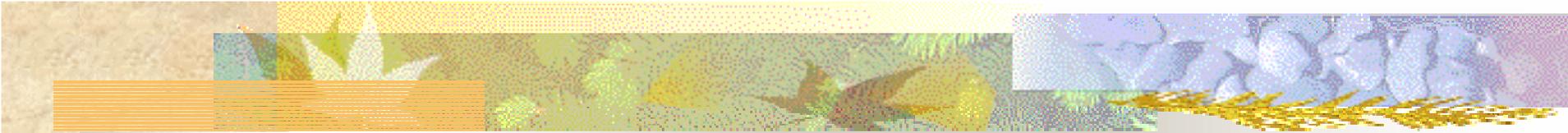
- How Rx will be withdrawn
- What to expect as Rx is withheld/withdrawn
- What likely course of illness will be
- How pain and distress will be managed
- Where they would like to die
- What religious/cultural issues are important for them to observe or participate in



Ways to improve Quality of Care as Rx is Withdrawn

Document:

- Patient's medical condition and reasons for withdrawing Rx
- Goals of ongoing Rx and care
- Way in which Rx will be withdrawn
- Way pain and distress will be evaluated
- Way pain and distress will be treated
- Way drugs used to treat pain and distress will be increased and reasons for increasing doses



Euthanasia

- Deliberate act undertaken by one person with the intention of ending the life of another person in order to relieve that person's suffering where that act is the cause of death (Special Senate Committee, Of Life and Death, June 1995)
- Illegal under the Criminal Code
- Minimum sentence is life imprisonment



Assisted Suicide

- Act of killing oneself with the assistance of another who provides the means, the knowledge or both (Special Senate Committee, Of Life and Death, June 1995)
- Illegal under the Criminal Code
- Fourteen years imprisonment



Arguments in Favour of Legislation

- Right to die
- Mercy and compassion
- Consistency
- Gain in trust in patient-physician relationship



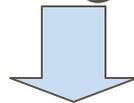
Arguments Against Legislation

- Sanctity of Life
- Value of suffering
- Violation of Hippocratic Oath
- Loss of trust in patient-physician relationship
- Abuse of power
- Cessation of research in palliative care
- Slippery Slope



Reasons for Requests in the Medical Literature

- Sense of loss or disintegration of self
- Fears of being a burden
- Loss of independence
- Poor pain and symptom control
- Fears of prolonging dying
- Fears of technological death



Really a call to improve quality of EOL Care