

## A SIX-STEP PROTOCOL

**Step 1: Clarify the Request.** Only when the patient's point of view has been characterized, will it be possible to talk about what suffering means to the patient and what assurances can or cannot be given

**Initiate/Encourage the Discussion.** When a request for hastened death is first received:

- Listen carefully to the nature of the request
- Ask open-ended questions in a calm and non-judgmental manner to elicit:
  - Specific information about the type of request that is being made
  - The underlying causes for the request
- Remember that while some physicians fear that talking about suicide or hastened death will increase the likelihood that the patient will act, this fear has not been substantiated. An open discussion is more likely to reduce the intensity of the request

### Ask Detailed Questions

- Once the underlying reasons are known, more directed questions could be asked
- During the course of the questioning, it is particularly important to learn whether the patient is imagining a future that is either unlikely, or easily preventable
- Several examples, and the common areas to which answers may point, follow:

"MD: "What makes you ask that?"  
-Desire for a pain-free death  
-Control over the dying process

MD: "What do you expect will happen without PAS?"  
-Understanding and expectations of the illness  
-Expectation of what dying will be like

MD: "What type of assistance do you want?"  
Pills, injection

MD: "Who do you want to be involved? Why?"  
Self, family member, physician

MD: "When do you think you want to die?"  
-Now  
-At some later point  
(Provides some indication of acuity)

MD: "What do you hope to accomplish?"  
-Freedom from pain, disability, bankruptcy, dependency, indignity  
-Removing burden on others  
(Provides some understanding of the patient's reasoning and what he or she is hoping for)

### Use Empathic Listening Skills

- As you listen to the answers, use the therapeutic effect of empathetic listening
- Avoid endorsing the request for PAS in a way that confirms the patient's perception that his or her life is worthless
- Remember that empathizing is not the same thing as agreeing
- Premature affirmation of any perspective can propel both parties to stark choices

### Be Aware of Personal Biases

- To respond effectively to the needs of the patient, the physician must be aware of:
  - His or her own biases
  - The potential for counter transference
- If the idea of suicide is offensive to the physician, the patient may feel his or her approbation and worry about abandonment
- Be open to the possibility that your personal reactions to the patient's suffering may give insight into his or her experience

**For Example...** If the physician feels weighed down by meeting with the patient, perhaps the patient is depressed

## Step 2: Determine the Root Causes

### Assessing the Underlying Causes of a Request for Physician-Assisted Suicide: A Brief Overview

- A request for PAS may indicate a failure to address the full scope of a patient's needs
- Focus on all 4 dimensions of suffering:
  - Physical
  - Psychological
  - Social
  - Spiritual suffering as well as practical concerns
- Among all the psychological and physical possibilities, give particular consideration to the possibility of clinical depression or anxiety as research indicates correlation between requests and their presence
- When evaluating psychological and social issues, explore the patient's fears about his or her future

### Assess for Clinical Depression. Clinical depression:

- Occurs frequently
- Is both under-diagnosed and under-treated
- Can be a source of intense mental suffering
- Can be a barrier to completing life closure and achieving a "good death"

Diagnosis of depression is challenging in patients with advanced illness

- The physical symptoms typically associated with depression (e.g., changes in appetite, weight, energy level, libido, or sleeping) frequently occur in these patients as a result of their illness
- Studies have shown that the screening question, "Do you feel depressed most of the time?" is highly sensitive and specific in the medically ill
- Also be alert to feelings of pervasive helplessness, hopelessness, and worthlessness. These feelings are not normal. Do not assume they are situational and leave them unattended

Treatment choices depend on time available

- Fast-acting psychostimulants

### Psychosocial Suffering, Practical Concerns

- Emotional and coping responses to life-threatening illness may include:
  - A strong sense of shame
  - Feelings of not being wanted
  - Inability to cope
- Adjustment to the losses that occur with advanced illness may be difficult:
  - Loss of previous function
  - Loss of independence

- Loss of control
- Loss of self-image
- Each change may lead to tensions within relationships that further increase isolation and misery
- Worries about practical matters can create considerable distress
  - Who caregivers will be
  - How domestic chores will be tended to
  - Who will care for dependents, pets
- If support is not forthcoming or is insufficient, suffering may ensue or increase

### **Physical Suffering**

- A host of physical issues may accompany advanced illness, including:
  - Pain
  - Breathlessness
  - Anorexia/Cachexia
  - Weakness/Fatigue
  - Nausea/Vomiting
  - Constipation
  - Dehydration
  - Edema
  - Incontinence
  - Loss of function
  - Sleep deprivation
- Their presence, particularly if they are unmanaged for long periods, may markedly increase suffering

### **Spiritual Suffering**

- The prospect of dying may evoke seemingly unresolvable existential concerns that are then experienced as suffering
- As illness advances and disability increases, the patients may come to question their sense of:
  - Meaning
  - Value
  - Purpose in life
- Patients may experience a sense of abandonment or punishment by God, which can result in:
  - Erosion of faith and religious beliefs
  - Anger

### **Common Fears**

- In addition to current concerns, many patients are fearful about what the future will be like
- They may worry about issues such as:
  - Pain and other symptoms
  - Loss of control or independence
  - Abandonment
  - Loneliness
  - Indignity
  - Loss of self-image
  - Being a burden to others
- While their thoughts may be unrealistic in the setting of quality care, understand that many have witnessed suboptimal care in others that fuels their fears and fantasies
- Direct questions may be adequate to assess a patient's fears
- If not, discussing a series of scenarios and preferences, as is done during advance care planning, may be helpful
  - When personal values and goals of care are being discussed, clarify the things the person most wants to avoid
  - This may help to preempt unrealistic fears

### **Step 3: Affirm Your Commitment to Care for the Patient**

- Patients facing the end of life often have fears of abandonment
- Listen to and acknowledge expressed feelings and fears
- Make a commitment to help find solutions to the issues of concern, including:
  - Current concerns
  - Anticipated concerns
- Reinforce that you want to continue to be the patient's physician until the last possible moment
- Explore options to allay immediate concerns and fears
- As a request for hastened death affects everyone who is close to the patient, a commitment to the patient also affirms a commitment to the family and those close to the patient, including other caregivers

### **Step 4: Address the Root Causes of the Request. Overview**

- This section provides a general framework for addressing some of the potential root causes for a request for hastened death in each dimension of suffering
- Start by discussing the patient's health care goals and preferences, explaining palliative care approaches and services, and describing the legal alternatives to PAS
- Remember that some patients may not trust either individual health caregivers or the health care system to meet their needs. This may relate either to culture or past experiences
  - It helps to discuss this lack of trust with the patient at the outset, so that the issues can be understood, if not dealt with, early
- In order to effectively address the issues that are often the root cause(s) of requests for Physician-Assisted Suicide, physicians should have skills in and knowledge of:
  - Withdrawal, withholding treatment
  - Aggressive comfort measures
  - Palliative care principles
  - Local palliative care programs

### **Addressing Psychological Suffering**

- As psychosocial suffering leads to many of the requests for physician-assisted suicide or euthanasia, its management warrants considerable attention
- As each patient's emotional response to illness can be profound and coping responses varied, they will require careful exploration in a positive and understanding way
- Start by assessing and aggressively managing any:
  - Depression
  - Anxiety
  - Delirium
- Consider the need for supportive counseling, which:
  - Involves active listening and acknowledgment of the patient's feelings. May be:
    - Woven into general care
    - Provided more intensively through dedicated individual or group counseling
- Consider using other members of the multidisciplinary team or outside specialists as resources
  - Social workers and chaplains trained in supportive counseling can provide considerable assistance.
  - Referral to trained counselors, psychologists, or psychiatrists may be required if the issues are complex and/or the risks high

### **Addressing Social Suffering, Practical Concerns**

- Stresses and conflicts in the social dimension or practical aspects of a person's life can have profound effects on his or her will to live
- Express interest and inquire in detail about this aspect of the patient's life

- Specific areas to address include:
  - Family situation
    - What is the patient's family situation? Does he or she live with someone? Are family members supportive? Are there unresolved issues?
  - Financial situation
    - How is the patient's financial situation? Is health insurance available and sufficient?
  - Legal affairs
    - Are legal affairs in order? Does the patient have a...
      - living will? power-of-attorney for health care? power-of-attorney for business affairs? last will and testament?
  - Setting of care
    - Where would the patient like to receive care? Who is there to help?
  - Caregivers
    - Who will the caregivers be? Is there tension over the caregiving role for either party?
  - Domestic chores
    - Who attends to domestic chores such as cooking, cleaning, shopping, banking?
  - Dependents
    - Are there any dependents the patient cares for, or pets? Who will care for them if the patient is not able to?
- As this dimension often lies outside of the areas most physicians feel confident in addressing, consider requesting assistance from other members of the health care team, including:
  - Social work
  - Nursing
  - Chaplains
  - Occupational therapy
- Additional resources for help and support may be available:
  - In the community
  - Through a health care institution
  - From a local hospice or palliative care program

### **Addressing Physical Suffering**

- Multiple studies indicate that patients with life-threatening illnesses have many physical issues that are unaddressed. If left unmanaged for long periods, each can add considerably to a patient's sense of suffering
- Today, suffering from physical symptoms due to lack of management is inhumane
  - Modern medicine has more knowledge and tools than ever before to manage:
    - Pain
    - Anxiety, delirium, depression
    - Other common physical symptoms
  - Each symptom needs to be pursued aggressively
  - Successful management often requires extensive and careful thought and individual clinical trials, until symptoms are brought under control
  - If a physician is inexperienced, consultation with expert colleagues should not be delayed
- Function is critical to maintain independence. Physiatrists, nurses, and physical and occupational therapists may be helpful and knowledgeable about the exercises and aids that can be used to optimize and maintain function, and ensure safety
- Sexuality and intimacy are integral aspects of each one of us, particularly through touch and the closeness to partners and family members we cherish. Illness and disfigurement may change the way people are able to interact. To establish individual desires and tensions, facilitate discussions between partners and key family members. Help them to look for alternatives that may be comforting

### **Addressing Spiritual Suffering**

- The spiritual dimension of human experience is universally challenged in the face of a life-threatening illness
  - Each person has a sense of meaning and purpose to his or her life, and a sense of where he or she fits into the grand scheme of things
  - This may have a frankly religious orientation or it may be expressed through faith or a personal sense of spirituality
  - Nevertheless, the transcendental dimension is present in each one of us and it is critical that this dimension be explored when a patient requests PAS or euthanasia
- Helping patients to establish or reestablish a sense of meaning and purpose is often fundamental to the relief of spiritual suffering. This may involve...
  - Encouraging them to reminisce with family and friends
  - Assisting with life closure, gift giving, and creation of legacies
- Consider your own expertise comfort level in dealing with these issues
  - Some physicians feel comfortable dealing with spiritual suffering
  - Others feel inexperienced and out of their depth
  - As these issues are critical and may be very time consuming, a skilled hospice chaplain who works with a psychiatrist or psychologist skilled in end-of-life care, may bring considerable skill and support to both the patient and the physician
- Do not make assumptions about clergy
  - While it would be ideal if the needed skills came from the patient's own pastor, do not assume that all members of the clergy are equally comfortable with the care of patients with advanced life-threatening illness
  - Like physicians, many have not received adequate training in chaplaincy issues and are ill equipped to deal with the profound conflicts surrounding requests for physician-assisted suicide or euthanasia

### **Addressing Fear of Loss of Control**

- Explore areas of control, independence
  - The autonomy and control that each one of us has over our lives and affairs is central to our personhood
  - While this need for control varies in some cultures, it is a central feature of Western society
  - For many, independence is profoundly challenged by illness that is debilitating and deprives them of mastery or control over their day-to-day activities and their sense of future
- Be aware that this fear of loss of control may be further heightened by:
  - Fears that their expectations and needs won't be addressed, or
  - Fears that people will do things to them that they don't want (eg, forced feeding, invasive procedures, life-sustaining therapies, etc)
- Remember that the specific issues that are most important for each person to control are unique to that individual. They may include a whole range of issues such as choices about:
  - Day-to-day activities and experiences that are meaningful
  - Therapies
  - Settings of care
  - Caregivers
- The physician can be instrumental in helping the patient to continue to realize as much control as possible, given the changes in function that are likely to occur
- This may take unusual flexibility on the part of the physician and the health care team
- Specific actions you can take include:
  - Educate and help the patient plan for aspects of medical care that are rightfully under his or her control:
    - The ability to accept or refuse any medical intervention
    - Choices about life-sustaining therapies
  - Encourage the patient to:

- Select personal advocates and proxy decision-makers
- Prepare advance directives
- Plan for death, including:
  - Funeral plans
  - Wills
  - Disposing of personal belongings after death
- Teach family members and caregivers alternate approaches to caregiving that optimize patient participation in decision-making

***For example...*** Instead of "doing without asking," encourage family and caregivers to "ask before doing"

### **Addressing the Fear of Pain and Other Symptoms**

While patients may find current symptoms acceptable, they frequently fear a future where symptoms will be out of control and unbearable, particularly when they are dying. As a physician, you can:

- Reassure the patient that most all symptoms can be well controlled
- As appropriate, discuss alternate approaches to symptom management, including anesthesia
- Ensure that patients and families know that pain does not get suddenly worse as death approaches
  - Help them to understand the difference between pain and terminal delirium, particularly if they have known someone else who had a difficult death
  - As many patients fear adverse effects of medications, particularly drowsiness and confusion, discuss their management should they occur
- The possibility of end-of-life sedation, should pain or other symptoms be unbearable for the patient and unmanageable by experts, may be explored with the patient and family during advance care planning discussions
  - Some patients and families will find the possibility reassuring
  - Others will not want to consider it
- Most importantly, during all of these discussions, make a commitment to keep working to manage the symptoms until they are satisfactorily controlled. Patients fear being told, "I'm sorry, there's nothing more I can do."

### **Addressing the Fear of Being a Burden**

In several studies, one of the things patients fear most about a life-threatening illness is the prospect of being a burden to others. This is, in some ways, a corollary of the fear of losing control, particularly as our culture generally does not value being dependent on others

- Try to establish why the patient does not want to be a burden
- Address caregiving issues
  - If there are caregiving issues, facilitate a discussion between the patient and family
  - In many cases, families are willing and eager to care for the patient and their desires simply remain unspoken
  - If patients and families are worried that family members will not have enough skill to provide adequate care, suggest home hospice care
  - This is the fundamental goal of the home hospice team, to help educate, train, and supplement the family in the care of the patient
  - Alternate care settings can be arranged as a backup if care at home does not go as planned
  - Home hospice agencies must make provisions for brief periods of respite care if it is needed
- Address financial issues
  - If there are financial issues, help the patient find information and resources that will be acceptable
  - Remember that many people are unaware of the services available

- Consult with social workers and nurses, who can:
  - Help find solutions to issues
  - Provide training and backup to unskilled family members
  - Serve as a significant resource to the physician to help lessen the patient's fear of being a burden

### **Addressing the Fear of Indignity**

- Explore what loss of dignity means to the particular patient. Potential elements of this complex concept may include:
  - Being dependent
  - Loss of control
  - Being a burden
  - Being embarrassed
- Once the issues are clear, explore approaches to caring and resources that can help to maintain dignity. Ensure that:
  - The patient, where possible, participates in decision-making
  - Family members and caregivers know how to approach and address these issues
  - Everyone has permission for their roles and each task that they will do
- Reassure the patient that he or she has dignity in your eyes

### **Addressing the Fear of Abandonment**

For some patients, their worst possible fear is abandonment—by families, their friends, their physicians, or other health care professionals. This fear can be heightened by the realization that others cannot cope with the illness and the changes it brings, or the role of being a caregiver

- Explore this fear in detail with the patient and family in a family conference
  - Try to establish how realistic the patient's concerns may be
  - If tensions seem high or there are indications that family and friends are not coping, a meeting with everyone may be helpful to assess the situation
- If caregiving is becoming onerous, offer a respite break or an alternate setting for care
- As appropriate, try to connect families to available supports in the community, particularly those provided by the interdisciplinary teams available through hospice and palliative care programs
- Above all, when addressing fear of abandonment, reassure the patient about your plans for being involved in ongoing care

## **Step 5: Educate the Patient About Legal Alternatives for Control and Comfort**

### **Dealing With Misconceptions**

- When making a request for PAS, patients may have misconceptions about the benefits of their requested course of action
- Some may be unaware of what emotional effort goes into planning for physician assisted suicide or euthanasia
- Others may be unaware of the risk of emotional consequences to:
  - Family and friends
  - The personal legacy they hope to protect

### **Legal Alternatives to PAS**

- Patients may also not be aware of the legal alternatives available to them
- This may be particularly true if they have not participated in discussions to clearly define their goals of care and treatment priorities
- As part of the process of discussion, planning, and decision-making, the physician may wish to discuss the 4 following legal alternatives to PAS:
  - Refusal of Treatment
  - Withdrawal of Treatment



- Declining Oral Intake
- End-of-life Sedation

### **Refusal of Treatment**

- Patients should be clear that they have the right to consent to, or decline, any:
  - Treatment (e.g., surgery, chemotherapy, pacemakers, ventilators, medications including antibiotics, IV fluids)
  - Settings of care (e.g., hospitalization)
- They should also be aware that their choices to decline particular therapies would not affect their ability to receive high quality end-of-life care. For more information on refusal of treatment see the section on Sudden Illness

### **Withdrawal of Treatment**

- Patients should be clear that they have the right to stop any treatment at any time. This includes the cessation:
  - Of fluid and nutrition
  - Either enterally or parenterally
- Again, they should know that their choices to withdraw particular therapies would not affect their ability to receive high quality end-of-life care. For more information, see the section on Withholding, Withdrawing Treatment

### **Declining Oral Intake**

- Patients should be clear that they might choose to decline regular oral intake of food and/or fluids. Just like any other medical decision, a competent individual can determine what goes into his or her mouth
- Based on the principle of bodily integrity, force-feeding is not acceptable
- To assist with decision-making, patients will usually benefit from knowledge that he or she will not suffer from dehydration or starvation
  - A detailed discussion of their potentially protective properties and the appropriate management of symptoms should they occur will usually allay fears and reduce anxiety considerably
- As fluids and food are synonymous with life, and culturally ingrained, family and caregivers will likely need considerable education and support if the patient decides to cease oral intake
  - Encourage them to always have food and water accessible so that the patient can change his or her mind at any time
  - Discuss the potential for anger and resentment if they persist in badgering or attempting to force things on the patient
  - Above all, recognize their desire and need to give care and refocus them on activities that will be beneficial to everyone

### **End-of-life Sedation**

- For the rare patient with unbearable and unmanageable pain, or other intractable symptoms, who is approaching the last hours or days of his or her life, the induction and maintenance of a state of sedation may be the only remaining option
  - Sedation in the imminently dying is intended to produce a level of obtundation sufficient to relieve suffering without hastening death
  - This approach has a firm ethical basis that derives from the importance of intended effect over possible secondary and unintended consequences.
- Before end-of-life sedation is considered:
  - It should be clear to the attending physician, members of the health care team and consultants with expertise in palliative care that all available therapies have been tried to their limits without benefit
  - Individual physicians should not consider this issue without consulting others
  - This is not an alternative to high quality palliative care or limitations in available resources imposed by institutions or health care funders

- If no other options are apparent, consider how the patient and family might react to this option. As a guide, use evidence from:
  - Advance care planning discussions
  - Recent statements they have made
- If the team feels that the patient and family will not perceive the discussion as a sign of abandonment
  - Discuss the option with them
  - Solicit their opinion
- Before making a decision:
  - It should be clear to everyone that the intent in offering sedation is to make the patient comfortable during the last days of his or her life when all other alternatives have not been successful
  - If anyone perceives that the intent of sedation is to kill the patient and not simply relieve suffering, the approach should not be pursued
- If the patient and family find the option acceptable and the patient chooses to receive sedation:
  - Intermittent or continuous intravenous or subcutaneous infusions of midazolam, lorazepam, propofol, or barbiturates have been used successfully to induce sedation and reduce awareness
  - Opioids are not recommended if the primary goal is to induce sedation. However, if the patient has been in pain, opioids will need to be continued so that the unconscious patient will not experience pain. Follow standard opioid dosing guidelines and alter doses if renal clearance decreases
- If the patient dies while receiving sedation and appropriate doses of medication were used, the death should be attributed to the underlying illnesses, not the sedation

#### **Step 6: Consult With Colleagues**

- A request for physician-assisted suicide may be one of the most challenging situations a physician will face in his or her practice of medicine
- Unfortunately, it is in precisely these situations that physicians may hesitate to involve someone else. Reasons for such reluctance may include:
  - Personal issues raised by the subject
  - A conviction that it is not appropriate to talk about death
  - Concerns about the legal implications of the situation
- As requests for hastened death can have considerable personal, ethical and legal ramifications, they should not be dealt with in isolation, but rather with the support and input of at least one trusted colleague or advisor
  - This person may be:
    - A mentor
    - A peer
    - A religious advisor
    - An ethics consultant
  - Physicians may also find considerable support from
    - Nurses
    - Social workers
    - Chaplains
    - Other members of the interdisciplinary team who are involved in the patient's care

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