

## HOW TO CONDUCT A COMPREHENSIVE ASSESSMENT: NINE DIMENSIONS

### Step 1. Illness/Treatment Summary

The patient seeking end-of-life care will likely have a long history with multiple interventions. A complete history should include:

- Primary diagnosis
  - Illness's effects
  - Treatment's adverse effects
- Secondary concurrent illnesses
- Treatment summary

Before moving beyond assessment to making a care plan for the patient:

- Consider whether previous treatments were appropriate based on:
  - Their known effectiveness
  - Patient preferences
- Verify that appropriate curative treatments have been considered
  - If not, present these options to patient and proxy
- Consider that efforts to control the underlying disease may be appropriate even in advanced stages of illness
  - Especially true with pediatric patients, whose parents may desire curative or life-prolonging therapy even in the face of poor prognosis

### Step 2. Physical Assessment: General Guidelines

- Physical assessment at end of life differs from a standard patient assessment
  - Organized by **symptoms** and **functional activities** rather than by organ system or anatomy
- After assessing symptoms and physical impairments, a physical examination can be conducted to:
  - Confirm findings from the history and provides baseline clinical information
  - Establish a relationship that includes therapeutic touch
- Minimize diagnostic tests
  - Conduct only if the results will clearly affect or help determine the therapeutic plan
  - Remember that burden associated with diagnostic tests may conflict with a goal of maximizing comfort

### Symptom Assessment

The following symptoms are common during the last phase of life. Be sure to ask about each one:

- Pain
- Weakness/fatigue
- Breathlessness
- Insomnia
- Weight loss
- Confusion
- Constipation
- Anxiety
- Nausea/vomiting

- Depression

### **Symptom Causes**

- For every symptom, multiple potential causes should be considered, including:
  - The primary illness
  - An effect of therapy
  - Psychological, social, spiritual, cultural issues
  - Another medical condition
- For more information on how to thoroughly assess each symptom and its causes, see:
  - Module 4: Pain Management
  - Module 6: Anxiety, Delirium, Depression
  - Module 10: Common Physical Symptoms
  - Module 12: Last Hours of Living

### **Why Use Pain as a Model for Symptom Assessment?**

- High prevalence
- Usually can be well controlled
- Often under treated
- Adequate treatment requires adequate assessment
- Gateway to assessment of other symptoms

### **Overview of Pain Assessment**

- Pain is prevalent
  - Present in up to 90% of patients with advanced cancer or AIDS
  - Similar prevalence rates reported in pediatric and geriatric patients
- Pain assessment relies on patient self-report
  - Symptoms are inherently subjective
  - No reliable way to assess what the patient is experiencing other than by asking the patient
  - Patient self-report is the "gold standard" for assessment
- Pain assessment conducted using the methods outlined below will:
  - Help the physician gain a clearer understanding of diagnosis
  - Convey to the patient that the symptom is important to the physician

### **Aspects of Pain Assessment**

#### **Location**

- Where does it hurt most? Does it go anywhere?
- How does your pain change over time?
- How long have you had this pain?
- Did it begin gradually or all of a sudden?
- Does it come and go, or do you have it all the time?

#### **Quality**

- What words might you use to describe the pain?

#### **Severity**

- How bad is it on average?
- At its worst?
- Is it progressing or remaining stable?

## Modifying Factors

- Does it feel better when you're in a certain position?
- Do you notice any change with [various activities]?

## Impact on Function

- To what extent does the pain interfere with your normal activities?
- What about your sleep?
- Your ability to walk?
- Your relationship with others?

## Effect of Treatments

- What have you been doing for the pain?
- Have you taken any medications?
- How much relief does that provide?

## Patient Perspectives

- What do you think is causing the pain?
- What does the pain mean to you?
- Would you like me to prescribe something?

## Assessing Pain when the Patient Cannot Communicate Verbally

- Pain assessment in the non-cognitively intact person, such as an elderly patient with dementia, is challenging
- Similar challenges are present in pre-verbal children
- Behaviors such as grimacing, moaning, or crying may be the only way to assess pain
- Rely on experienced colleagues to help with assessment

## Tools for Pain Assessment

- Symptom severity is an important aspect of assessment
- Despite being subjective, patients can accurately and reproducibly indicate the severity of their symptom using a scale
- Scales for pain:
  - Have been well validated as tools
  - Help to assure that pain is adequately assessed
  - Enhance the ability of the patient to communicate severity to health care professionals
  - Enhance communication of severity between professionals
- Scales in use include:
  - Numerical scales (0–10)
  - Visual analog scales
  - Faces scales (showing a sequence of faces in a row from happy to intermediate to sad)
- The specific scale used is less important than using one in a consistent way over time
  - Some patients have trouble with the concept of rating pain on a numerical or visual analog scale
  - Using a more concrete scale such as the Borg Faces Scale may be helpful, particularly with children
- The **Brief Pain Inventory (Short Form)** of the Pain Research Group, University of Wisconsin, Madison is one example of a pain assessment tool. A copy is included in the Resources section of this Module

- A similar approach to that described for the systematic assessment of pain should be applied to the assessment of all other symptoms
  - When assessing a patient with multiple symptoms, it is extremely helpful to use a standardized form that can be used to track the symptoms over time
  - The **Memorial Symptom Assessment Scale** is an example that is included in the Resources section

#### **Functional Assessment. Areas of Function to Assess and Questions to Ask:**

- Motor function
  - Can the patient move around?
- Sensory function
  - Can the patient see or hear well enough?
  - Is he or she safe?
- Effect on activities
  - Can the patient move around?
- Effect on relationships
  - How are physical aspects, in particular, sexual function, affected?
- Patient perspectives

#### **Step 3. Psychological**

##### **Cognition**

- Ask screening questions to assess delirium, dementia. Are there times of confusion? Hallucination?

##### **Affect**

- Ask about mood—anxiety, sadness
- Depression and anxiety are among the most prevalent and most under diagnosed symptoms in patients facing the end of life

##### **Emotional Responses to Illness**

- There is always an emotional response to serious illness; it challenges a person's sense of themselves and their role in life
- Common emotional responses prompted by illness include:
  - Avoidance, denial
  - Fear, anger
  - Lability, irritability
  - Intellectualization
  - Grief
  - Acceptance, spiritual peace
- Ask about how the patient is responding to the fact of being ill
- Consider naming some common responses, such as:
  - Anger
  - Grief
  - Instability
  - Tranquility
- Be aware of common patterns of emotional response to illness:
  - Some people move through stages of shock, struggle, and eventually reach resolution
  - Most people move between a range of emotions and not always in a predictable order
  - Emotions come in surprising waves and/or can be persistent
- It helps to give the patient (or parent if the patient is a child) a sense that their emotional response is normal

- One way to do this is to inquire about his or her emotions, and then actively listen to the patient's responses
- It frequently helps the patient if the physician, or other health care giver, identifies the emotion, acknowledges it in an accepting way and thereby normalizes it
- In the case of a dying child, the emotional responses of the parents and the siblings are particularly relevant, since they directly affect the child as caregivers
  - There needs to be attention from members of the psychosocial team to these adults and children, at an age-appropriate level

### **Coping Responses**

- Assess the individual and determine:
  - Whether the patient is coping adequately
  - Whether referral should be recommended
- Do not hesitate to ask screening questions about suicidal ideation
  - As a routine question among others, or indeed as an explicit and exploratory discussion, there is no evidence that it fosters thoughts of self-harm
  - Rather it sets the groundwork for later discussions if they are needed, and it allows for self-expression, which can be therapeutic

### **Fears**

- Almost all patients have fears for the future as they face the end of life. Common fears include:
  - Loss of control
  - Loss of dignity
  - Loss of relationships
  - Fears of physical suffering
- In tailoring a therapeutic relationship and a plan of care it is critical to know what it is that the patient tends to fear

### **Unresolved Issues**

- Unresolved issues in personal matters and especially in relationships are a prominent part of the experience of patients at the end of life
- You may discover that what stands between the patient and a comfortable frame of mind is an unresolved issue
- These issues have to do with:
  - Settling old feuds
  - Making or receiving last visits
  - Completing a life-time project or piece of work
- In any case, creating a plan of care that allows for that work is important
- These issues are rarely apparent to a physician unless questions directed to this area are asked. Questions to Assess Unresolved Issues at the End of Life might be:
  - Is there something that you would like to do before you get too sick?
  - Many people have old differences they would like to settle before they die. Do you?
  - Many people have places or people they would like to visit. Do you?
  - Some have a piece of work they would like to finish. Do you?
  - In what ways has this illness affected you emotionally?
  - Are you doing things that you enjoy?
  - How has your mood been lately?
  - How have you been coping with all of this?
  - How have you handled stress in your life?
  - Are you concerned about being a burden to others?
  - Do you feel in control of your life right now?
  - Have you thought about taking your child on one more trip before she dies?
  - I think your child could manage a few half-days in school each week. Do you think that would help him?

#### **Step 4. Decision-Making Capacity**

- Assessment of decision-making capacity:
  - Follows naturally from a psychological assessment
  - Is fundamental for planning care
- In order that decisions can be made with the patient's (or parents' if the patient is a child) authentic understanding and agreement, it is important to:
  - Follow the necessary steps for information giving
  - Be sure that the patient has the capacity to give meaningful consent

#### **Capacity/Competence. We can think of capacity in two ways:**

##### **Global Incompetence**

- Patients who are globally incompetent:
  - Are not competent in any area of functioning
  - Cannot handle their own affairs and must rely on others
  - Cannot give meaningful consent to any particular health care decision
- Under such circumstances, prior preferences must be considered, as expressed:
  - In advance care planning documents or conversations (see Module 1: Advance Care Planning.)
  - By proxies using substituted or best interest judgments
- However, among patients with advanced illness, it is quite common that the patient has some compromised mental function without being globally incompetent
  - Capacity may only be limited with respect to questions whose answers rely on careful analysis.
  - Decisions based on firmly held beliefs may still be authentic
  - Consequently, it is generally helpful to include the patient as much as possible even when there is some mental compromise

##### **Decision-Specific Capacity**

- A patient who does not know where he or she is, and who can no longer manage his or her own affairs, may nonetheless have deep and meaningful insight into whether or not an amputation, intubation or some other major medical intervention is acceptable
- To afford that individual the full patient role in informed consent, the physician needs to determine whether the patient can:
  - Understand that he or she is authorizing the decision
  - Demonstrate that he or she is making accurate and rational inferences with the information given
  - Demonstrate insight into the consequences of the decision
  - Be free of coercive influences
- For example...If the patient has a near certain progression to sepsis and death in the absence of amputation:
  - Capacity to decide must be in doubt if:
    - The patient says that amputation is unnecessary for survival
    - The patient agrees with the amputation but seems to think this is someone else's operation or that the decision is not his or hers to make
  - If, on the other hand, the patient holds the view that death is better than amputation at this stage, a decision not to operate might be understood to reflect rational use of the information
- If a patient is declining life-prolonging intervention in circumstances that include a strong sense of family burden or professional abandonment, such a decision may be unduly influenced by others' agendas and should be carefully revisited in order to reduce and separate out conflicting interests from those of the patient

- If capacity is absent for the decision at hand, involve the proxy and share the decision-making in the usual fashion, with the proxy speaking in the patient's role

### **Goals of Care**

- Whether you are working directly with the patient or with the patient's surrogate, assess what are the goals for care
- If a patient has made the transition away from hope of cure to a focus on quality of life, it is important to relate goals of care to matters of personal meaning
- Ask the patient what he or she thinks are the most important things to accomplish now
- A range of possible goals should be explored, from aggressive comfort care to prolonging life until a certain meaningful event (see Module 7: Goals of Care.)

### **Advance Care Planning**

- Planning ahead for future care is only a small step from assessing goals for present care
- Timing of the advance care planning assessment:
  - Wherever possible, start the discussion at the initial assessment
  - This assessment may be left for a subsequent visit depending on:
    - The stamina of the patient
    - His or her expectations
- Pick a couple of likely scenarios, given the patient's current illness, and ask about:
  - What would be the goals for care in such a circumstance
  - A few key treatment decisions
- Offer a worksheet or document to record the preferences for future care

### **Step 5. Communication & Information Sharing. Does the Patient Have Someone to Talk To?**

- Whether a person is a 'talker' or a 'silent type', communication happens and it matters
- Most people do better if there is someone to share difficulties with
- Assess whether the patient have someone to share fears with? Talk to? Plan with?
- Identify who this person is for the patient. Keep in mind that it may be family, but it may not
- One of the most challenging aspects of end-of-life care is when the patient is alone. Then, the physician, and members of the health care team become critical components of support

### **Does the Patient Understand You?**

- Accurate information generally leads to the best outcomes
- Misunderstandings over information are usually problematic
- As part of routine interaction with the patient, ask if the patient understands what is being said and if they have answers to all their medical questions
- Is the information clear? Understandable?

### **What Does the Patient Want to Know?**

- Keep in mind that there are different personal styles of information sharing
- Ask the patient whether he or she wants a lot of information or not so much

### **Who Else Should You Talk to?**

- Be aware that there are different family styles of information sharing
- Ask the patient how he or she wants to involve family and friends in information about the illness.

- Be particularly attuned for difficulties if the patient is keeping his or her diagnosis a secret, or if the family is doing the same in reverse
  - In such cases, it can be helpful to ask [the informed party] if you can check with [the uninformed party] to see how much information they would like to have
  - Sometimes it helps to organize a family meeting where the physician can help "tell" the information and ensure that all hear the same information at the same time
  - Social workers can be particularly helpful in this regard
  - This is the only aspect of confidentiality that is quite often different from other aspects of patient care
- If language is a barrier, try to find a professional translator. See Module 2: Communicating Bad News

### **Step 6. Social. Introduction to Social Assessment**

- Illness impacts the social aspects of life
- Conversely, social circumstances impact illness
- The discipline of social work should be appropriately integrated into the treatment team to assist the patient, family, and physician
- However, outside of hospice and a few other programs, patients with serious illness do not receive comprehensive social assessment by a qualified social worker as a routine part of medical care
- Therefore, while the physician cannot perform the work of a social worker, the physician should be able to make an initial assessment of the patient's social needs
- The following areas of a person's social environment are relevant to the evaluation of suffering in the social dimension:
  - Family and family dynamics
  - Community support available to the patient
  - Financial resources available to the patient

### **Community**

- Some cultures have a more positive attitude toward care of the dying than others, but in general in the United States, there is little care offered routinely to the dying
- A tiny percentage of life-threateningly ill patients get practical assistance from their community
- However, services may be available and should be sought wherever possible
- Again, social workers may know much more than the physician about a community's resources
- Examples of community resources may include:
  - Many religious communities from all denominations have not only a tradition of care, but also have service systems
  - There are disease-based advocacy groups that offer practical advice in some cases
  - Other local resources: library, reading services, work-site, school, neighborhood
- Physicians who take the trouble to contact, or ask a member of the team to contact, possible sources of community support may find that there is a network of care that springs up

### **Financial. Spending Down**

- About 30% of families with a life-threateningly ill member spend a considerable portion or all of their life savings for the care of the patient
- A similar percentage loses a major source of family income due to the illness
- The result may be significant economic hardship

### **Medical Bills**

- Patients often receive medical bills that they do not understand and cannot pay
- Some may be reimbursed slowly, but patients who have prided themselves in keeping up with the bills may feel shame



## **Family Sacrifice**

- A major source of shame and even desire to hasten death stems from the financial burden on family members
- The desire to leave a financial legacy is strong
- Savings for the grandchildren or for education may be spent on medical care, much to the misery of the family and the patient

## **Step 7. Spiritual Assessment. Importance of the Spiritual Life**

- Each person has a spiritual or transcendent dimension to his or her life
- Physicians often hesitate to inquire into this universal dimension of human experience, yet studies suggest patients welcome the inquiry
- Spiritual life is understood by some in terms of religious feeling, and by others in terms of personal meaning in a larger context
  - We mean here to cover either interpretation of the term
  - Find the interpretation most fitting to the patient
  - In either case there is no need to emphasize a mysterious aspect to this part of a person's experience. It is a universal and important part of each individual's life
- Individuals who report a strong spiritual life often also report:
  - A greater sense of purpose
  - A greater sense of having come to terms with dying
  - Better communication
  - Better relationships
- The physician should bear in mind the possibility that patients can experience significant spiritual growth and gain meaningful fulfillment during their last stage of life
- The physician should know:
  - How spiritual this patient has tended to be in the past
  - How inclined toward spiritual life he or she now is
  - Whether or not he or she would like (or has) a pastor to visit
  - Whether there are religious rituals that are important to the patient

## **Meaning of Illness and Fears**

- Patients facing life-threatening illness often think about questions that they do not articulate easily or freely
- It often requires someone, such as the physician, to give permission
- Nearly universal questions include:
  - What will happen to me?
  - How will the illness proceed?
  - What will happen to my child?

## **Fears and Concerns about Death and Dying**

- Patients frequently will be thinking about death and dying, with questions such as:
  - How will I die?
  - Where will I die (home, nursing home, ICU, hospice etc.)?
  - What do I need to do (estate planning, life review, advance care planning etc.)?
  - How will my child die? Where will my child die?
- The physician may give permission for people to talk about these things by introducing the subject in a general way by saying: "Many people in your situation think about dying. Is that something you are thinking about?"

## **Changes and Losses**

- As patients face these questions, they also have to adjust to major changes and losses
- In their personal world, they will likely be thinking:

- Who will care for the people I love that depend on me?
  - Who will care for me?
  - Will I be a burden?
  - Will they still love/respect me?
  - What about my job?
- Parents of a dying child will be thinking:
    - How can I go on without my child?
    - How can I let my child die?

### **Loss of Control**

- People face, or fear, loss of control in multiple spheres
- Plans are trumped by the illness
- Independent people who have never considered being otherwise now face dependence
- Loss of body control, including the ability to feed, bath, and toilet oneself, is certainly a frequent concern
- These losses of control are associated in many people's mind with indignity and shame

### **Spiritual Activities. Importance of Religion**

- While it is helpful know the religion and religious denomination a person affiliates with, the degree to which religion is important must be evaluated separately. Ask questions about:
  - How often the patient has gone to services in the past and whether he or she would like to do so now
  - If there are particular prayers or scriptural resources that mean a lot to the patient that he or she may need help with
- Some patients engage in spiritual activities that are outside of organized religion. The level of activity in these pursuits is also relevant

### **Religion and the Patient-Provider Relationship**

- Occasionally, physicians feel comfortable praying with a patient
- Many patients would like their physician to do so
- This is not a necessary part of the patient-physician relationship
- However, it can be helpful if the physician is comfortable allowing the patient to express religious feeling
- The physician should be sure that the best available resources have been made available to the patient for his or her spiritual care

### **Clergy**

- Training in end-of-life care for clergy is not more developed than for physicians
- Many pastors working in the community have not received any specific training in end-of-life care
- However, end-of-life care is a part of most religious groups' framework
- Some patients will do better with their own pastor from their existing community as part of the treatment team
- Chaplains working in health care institutions:
  - May have much more training related to the spiritual care of people who are very ill
  - May be able to assist the patient and their local clergy

### **Rituals**

- Ask if the patient wants special prayers, declarations, rituals or last actions
- Someone should be sure that special prayers or actions and last prayers or declarations are carried out as the patient and family would like them to be

### **Spiritual Suffering and Spiritual Crises**

- Many aspects of advanced illness are not commonly appreciated to be fundamentally spiritual. Yet...
  - The search for meaning and purpose in life is a spiritual quest
  - Perceived loss of connection to a community or to a way of life may challenge the sense of meaning and purpose
  - Feelings of guilt or unworthiness may be manifestations of spiritual suffering
- If these aspects of spiritual suffering remain unrecognized, an appropriate plan for relief cannot be instituted
- Other aspects of advanced illness may be more conventionally noted to be spiritual. For example, patients may:
  - Question their faith
  - Express a desire for forgiveness and reconciliation
  - Feel abandoned by God

### **Approaches to Spiritual Assessment**

- Suspect spiritual pain in a patient who is facing a life-threatening illness
- Establish a conducive atmosphere that invites discussion of spiritual issues
- Express interest and ask specific questions, such as:
  - "Are you a spiritual person?"
  - "What role does religion play in your life?"
  - "Have you thought about what will happen after you die?"
  - "What are the things that matter most to you?"
  - "How have you tried to make sense of what's happening to you?"
  - "If you were to die suddenly, are there important things you feel would be left undone?"
  - "As you look back on your life, what has given your life the most meaning?"
  - "What are some of the things that give you a sense of hope?"
- Listen for broader meanings in patients' descriptions of their situation and how they are feeling
- Be aware of your own beliefs and biases towards religion and the spiritual dimension

### **Step 8. Practical Assessment. Caregivers: Who Cares**

- Ask about who is available to help with practical needs
- Most patients have or need someone to be a primary caregiver from their family and circle of friends
  - This is true even in a health care institution
  - When at home, the responsibility of caregiving can be a full-time and demanding task
- Studies show that most caregivers in the home are wives or daughters
- In the case of dying children caregivers are usually the parents
- Consequently, widows and single people may be more isolated and may have to rely on paid or volunteer community help to meet their needs if they are to stay at home

### **Patient-Caregiver Relationship**

- The relationship between the patient and the caregiver is important
- Some patients, and some caregivers, find the relationship difficult and it can leave a lasting negative impact on them
- Others do not want to have their families caring for them, no matter how loving or willing
- Likewise, some family members are unwilling to care for an ill relative
- To intervene positively, both the patient and the caregivers must be assessed

### **Assessing Unmet Needs**

- Even with a willing family caregiver at home, there are often unmet needs
- Ask how well the patient (or parent if the patient is a child) feels his or her needs are being met
- Be particularly aware of potential needs for: care on holidays, supplementary help, respite care

## **Domestic Needs**

- Transportation
  - As illness progresses, difficulty getting between the health care site and home is common
  - Ask about transportation needs
- Food
  - Difficulty obtaining food and/or cooking is also common
  - Ask: Who does the grocery shopping? Who does the cooking?
- Utilities
  - Keeping the lighting and heating paid for can be a challenge
  - Ask who is responsible for banking? Bill payment?
  - Ask whether basic needs for lighting and heat are being met

## **Dependents**

- Many patients may have others who are dependent upon them for caring, help, or survival
- Be aware that dependents may include: children, elders, others with illnesses or disabilities, pets
- When these people face dying, dependents have to be cared for in a different way and often by a different person
- Ask about family and what arrangements have been made

## **Step 9. Anticipatory Planning for Death. Current and Anticipated Losses**

- Patients and families members may grieve:
  - Over current loss of function
  - In anticipation of future loss
- Figuring out what grief is normal and what is complex or exaggerated and in need of intervention is an important part of assessment
- Planning ahead can be a very helpful coping mechanism for present and future losses
- Patients can usually readily relate their hopes for:
  - Life closure
  - Gift giving
  - Leaving a legacy
- In the case of a dying child:
  - Parents can think about plans for honoring their child's memory
  - The child may participate, depending on age
- Ask if the patient has, or would like to make, plans for:
  - Rites
  - Rituals
  - Funerals
  - Memorial services
  - Celebrations

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