

## **2011 MHPCO Annual Conference**

**April 19, 2011**

**Presentation Title: *"Spiritual Care Assessment: Measurable Goals and Outcomes"***

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### **Objectives:**

- 1. Describe the spiritual care assessment process as it relates to the 2008 Conditions of Participation (418.56). Explain spiritual care documentation of individualized and measurable goals and outcomes.**
- 2. Explain the importance of updating the plan of care for spiritual care and the need to document progression toward desired outcomes.**
- 3. Illustrate how to formulate goals and outcomes for spiritual care using various assessment tools.**

## ***SPIRITUAL CARE***

***The essence of spiritual caregiving is not doctrine or dogma, but the capacity to enter into the world of others and respond with feeling.***

### ***SOME DEFINITIONS:***

#### **Religion**

**A system of beliefs and practices related to the sacred, the supernatural and/or a set of values to which the individual is committed.**

#### **Spirituality**

**The dimension of human life that encompasses one's relationship with others, self, God or ultimate source of meaning. It involves seeking answers to one's ultimate questions about the meaning of life, illness and death.**

#### **Spiritual Care**

**Concerns the total person and recognizes the inter-dependence of body, mind and spirit. It further provides a dynamic resource for healing and wholeness by paying attention and responding to the needs of patients and families.**

**We need not feel that our job is to solve all spiritual problems, but rather to create an environment to nurture the person whenever possible. IT IS IMPORTANT when assessing spiritual needs to be able to recognize the resources the patient has identified as having helped to meet these needs in the past ("What nourishes our spirit?" vs. "What religion are you?")**

**The challenge of hospice is to sustain patients in a personalized environment that recognizes individual needs and attempts to reduce individual fears. Patients come with no hope of recovery from physical diseases, yet full of hope for relief from suffering.**

**§418.56(c) Standard: Content of the plan of care**

**L545**

The hospice must develop an **individualized written plan of care** for each patient. The plan of care **must reflect patient and family goals and interventions based on the problems identified in the initial, comprehensive, and updated comprehensive assessments.**

**Probes §418.56(c)**

- Determine through interview/observation and record review if the plan of care identifies all the services needed to address problems identified in the initial, comprehensive and updated assessments.
- Is there evidence of patients receiving the medication/treatments ordered?
- **Are plans of care individualized and patient-specific?**
- **Does the plan of care integrate changes based on assessment findings?**
- **Is there documentation to support that the development of the plan of care was a collaborative effort involving all members of the IDG and the attending physician, if any?**

**L548**

**(3) Measurable outcomes anticipated from implementing and coordinating the plan of care. Interpretive Guidelines §418.56(c)(3)**

The outcomes should be a measurable result of the implementation of the plan of care. The hospice should be using data elements as a part of the plan of care to see if they are meeting the goals of care.

**Probes §418.56(c)(3)**

**Are the outcomes documented and measurable? Look for movement towards the expected outcome(s) and revisions to the plan of care that have been made to achieve the outcomes.**

## In House Hospice Solutions Spiritual Care Audit Tool

Benefit election date

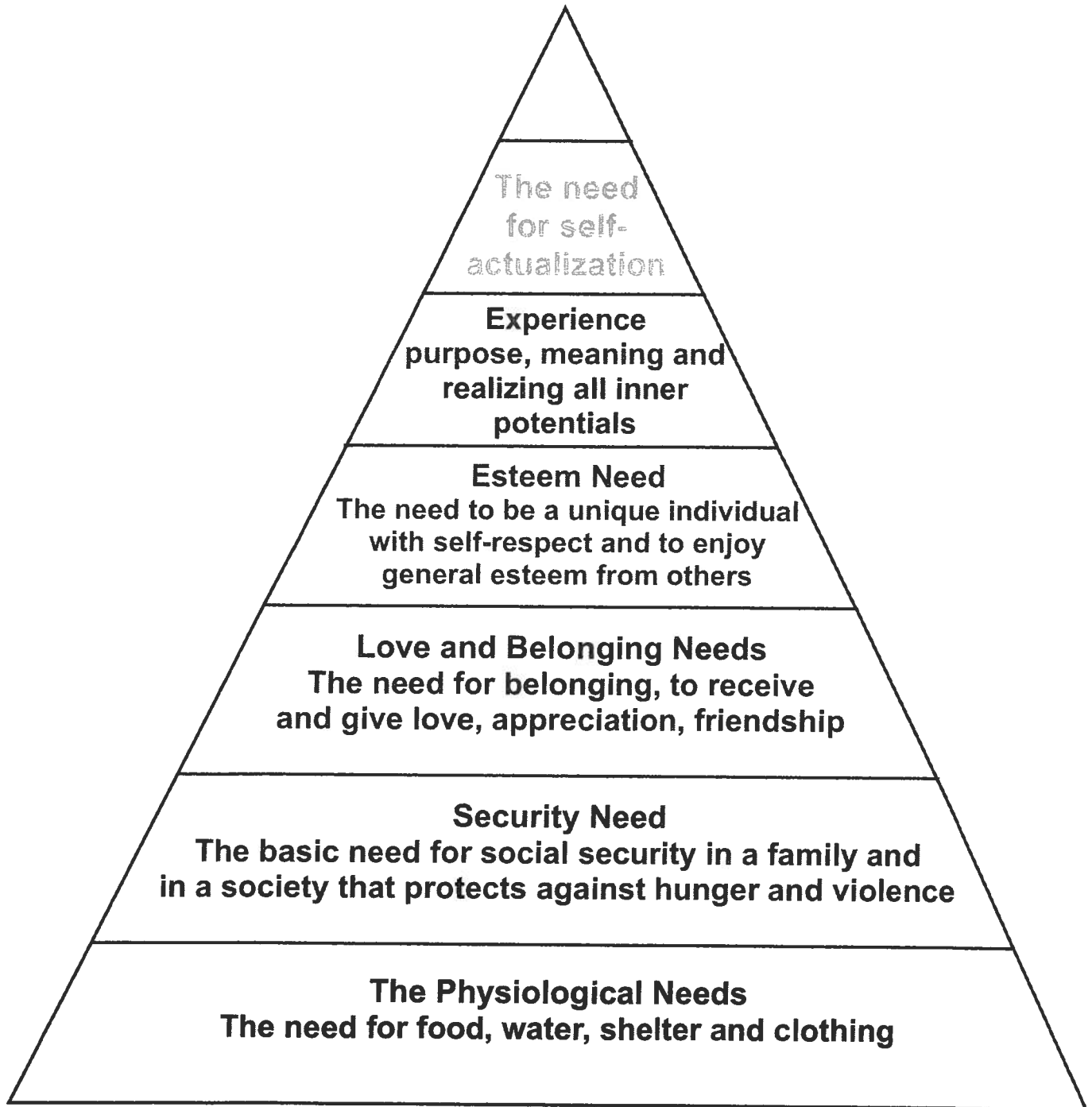
	Yes	No	N/A	Comments
Was the S/C assessment and plan of care <b>completed</b> within 5 days of admission?				
Is there evidence of specific, individualized and measurable goals formulated for spiritual concerns identified during the assessment and included in the IDG POC?				
Is the spiritual visit freq documented on the IDT poc updates? Are there visit notes present to meet the visit frequency plan?				
Was the Pain AD scale completed and if necessary, was the ECF RN and IHHS RN notified for comfort management?				
Is there evidence of the Chaplain conferencing with the facility staff and the IDG team?? (Noted on visit notes with Names and titles?)				
Are the S/C goals, issues, interventions, and/ or plans reported and documented on the IDG poc updates?				
<b>Totals</b>				

## Reflective Questions for Self-Disclosure (Spiritual Care PIP)

1. What is your present hurt/loss/disappointment?
2. Do you have any regrets? Resentments?
3. What is your greatest fear before you die?
4. Imagine you are unable to make your needs know<sup>^</sup>, what do you want others (i.e. family, friends, healthcare professionals) to know about you; your values, your daily routine/rituals, your interests, your likes and dislikes?
5. How will you be able to convey these needs that are unique to you?

**\*How can we learn/discover what our hospice patients needs/wishes/goals are when they are unable to express themselves? Particularly when there is no family or family is uninvolved.**

# Maslow's Hierarchy of Needs



*Advancing*  
**THE CONTINUUM OF CARE**



800-311-5365

# *Companioning Philosophy*

Companioning is about honoring the spirit;  
It is not about focusing on the intellect.

Companioning is about curiosity;  
It is not about expertise.

Companioning is about learning from others;  
It is not about teaching them.

Companioning is about walking alongside;  
It is not about leading or being led.

Companioning is about being still;  
It is not about frantic movement forward.

Companioning is about discovering the gifts of sacred silence;  
It is not about filling every painful moment with talk.

Companioning is about listening with the heart;  
It is not about analyzing with the head.

Companioning is about bearing witness to the struggles of others;  
It is not about judging or directing those struggles.

Companioning is about being present to another person's pain;  
It is not about taking away or relieving the pain.

Companioning is about respecting disorder and confusion;  
It is not about imposing order and logic.

Companioning is about going to the wilderness of the soul with another human being;  
It is not about thinking you are responsible for finding the way out.



-Alan Wolfelt

800-311-5365

## Goal Setting

### Spiritual Care and Assessment by Suzanne Weiss, BCC

The IHH philosophy and model of care promotes patient advocacy and patient choice in determining their plan of care. Goals should reflect patient/family choice. Once the assessment is completed and the problem/issue/opportunity is defined, then a goal should be formulated. Goals are action-oriented, outcome-based, and specific enough to be measurable. The goals provide *direction for the intervention*, therefore, the goal should start with a subject (i.e. Mary requested prayer) and the intervention should start with a verb (i.e. chaplain actively listened, explored, encouraged).

Patient/family goals focus on what the patient/family determine to be their wishes and choices and not what staff think they should be doing, as much as possible. It is helpful to use the patient's and family's own language to describe the goals.

#### *Examples of patient/family goal statements/desires/hopes:*

- Mr. S stated, "I want to keep Bessie at home until she dies."
- Mrs. T stated, "I want to live to see my daughter married in three weeks. After that, I will be at peace and ready to die."
- Mr. W wants to reconnect with his faith congregation by attending church when able and/or have the church elders visit him at home.
- Mrs. X wants to talk with her children to determine if her life work as a mother was meaningful to them.
- Patient wants to reconcile with his brother who lives out of state.
- Patient hopes she won't die alone - fears her family won't be with her at that time.

If you are having difficulty understanding patient/family/Cg oriented goals, try using these phrases to elicit goals from them:

- What is most important to you at this time?
- What are your concerns (right now/at this time/ in the future)?
- What can we do for you?
- What would be an acceptable pain level?
- What are the things you like to do? Are you able to do these things?
- What is your greatest achievement in life?
- What are the most important relationships in your life?
- What do you need to have spiritual peace with your disease process?
- What brings you comfort and strength?
- What do you feel you have control over...disease/pain/decisions?

## Outcome/Evaluation Language

Outcomes are the patient/family/Cg *responses to interventions*. Documenting the outcomes of spiritual care interventions is a critical step in the hospice documentation process. Whenever possible, it is helpful to include direct patient/family quotes. Documentation of outcomes helps to justify: palliative/hospice care services; the need for an interdisciplinary team care model; and show a patient/family focused ongoing, comprehensive assessment process. In addition, good documentation of goals and outcomes should present a picture of how patient/family are coping with/adapting to their situation. It should specify interventions utilized to meet goals and address patient/family needs and if they are effective.

In essence, documentation of individualized and measurable goals and outcomes for spiritual care must *"Paint the Picture"* so that anyone reading the chart will know what you know about the patient/family and why spiritual care services are needed.

### *Examples of Outcome/Evaluation Language:*

- Patient now reports pain at 2 out of 8. Patient states, "The pain is controlled and I can do my crafts again."
- Patient verbalized need for visits from his family
- Patient unable to verbalize feelings of loss, however when chaplain provided tactile touch and words of comfort, patient seemed to become more peaceful AEB decreased restlessness, shed tears, and grasped writer's hand firmly.
- As Mr. J's physical condition declines, his anxiety r/t the dying process and "fear of going to hell" seem to heighten. After several visits with chaplain who helped him identify these fears, he expressed interest in on-going spiritual care visits to help him continue exploring his relationship with God and the after life.
- Mrs. M. verbalized gratitude to writer for honoring her by listening to her life story. Her spirits seemed to be lifted as she recalled how her family, volunteer work and music have provided immense joy and meaning for her.

Outcomes may be more challenging to document with our less communicative patients. How can we learn more about these patients and what has given them meaning, purpose, joy, and comfort?

## **Additional Questions for Goals/Outcome Documentation**

- 1. Do your goals reflect the patient/family choices? How did you determine what the goals for s/c would be, especially for those patients who are nonverbal and/or have Dementia/Alzheimer's (i.e. conference w/ facility staff, family)?**
- 2. Are your goals action-oriented, outcome-based, and specific enough to be measurable? Remember that the initial assessment is only the beginning – each subsequent s/c visit is an on-going assessment.**
- 3. How do you know if your interventions are effective? Do you refer to the POC regularly to assess if the goals have been met/ resolved or if there is progress toward them? Are you documenting this progression toward goals on the IDG update form and collaborating with your team? Do you need to explore whether your patient/family are experiencing new issues/concerns and new goals may be needed?**
- 4. Does your documentation “paint a picture” so that it is evident that spiritual care services are needed and valuable?**
- 5. Do you have a plan for your next visit with the patient/family (always flexible and patient-centered)?**

## Assessment Questions for Spiritual Care Counselor – 6.4

By Suzanne Weiss, BCC Spiritual Care Consultant

### Sample Questions Spiritual Care Counselors Need to Ask Themselves:

- *Why am I visiting this patient? Do I have any preconceived beliefs/assumptions/biases about patient/family? Do I have a plan in mind as I begin visit? Do I hope to explore issues/concerns which patient expressed during previous visit? What are they?*
- *If patient is nonverbal or unable to express themselves, how can I learn more about them? Family members? Facility staff? IHH team? Are there spiritual/religious symbols or items in patient's room? Family photos or other items of value?*
- *If patient appears to be in pain/discomfort/anxiety, what may be causing it?*
- *Could there be any spiritual pain or suffering? How do I assess for spiritual pain once physical symptoms are addressed?*
- *What has helped patient cope with pain and suffering (physical, psychosocial, and spiritual - as they are interrelated!) in the past? Again, if patient is unable to verbalize and/or no family involvement, how do I find out?*
- *What are the quality of life issues for this patient?*
- *What tools and interventions do I offer patient which is in line with their faith and cultural beliefs and history?*
- *How can I measure effectiveness of my interventions?*
- *Do I have a plan (always flexible and patient-centered) for my next visit?*
- *Is emotional/spiritual pain sometimes necessary to facilitate healing? The role of the spiritual care provider is not to solve all spiritual problems, but rather to create an environment to nurture the person whenever possible. Patients come with no hope of recovery from physical diseases, yet full of hope for relief from suffering.*

**Spiritual Care Documentation of Individualized and Measurable Goals, Interventions, and Outcomes**  
(Including spiritual strengths – “healthy spirituality” and individualized needs/issues)

Spiritual Health is that aspect of our being which organizes the values, the relationships, and the meaning and purpose of our lives. It is the foundation for physical health and well-being.

**Characteristics of Spiritual Health: (“The Value of Spiritual Health”, Lawrence G. Seidl)**

- Is free of addictive habits
- Finds fulfillment in self, others, work, leisure, and/or higher power
- Accepts the limitations of humanity/themselves
- Takes time to meditate or communicate (“talk to”) with the Holy
- Finds illness as enabling, not disabling
- Knows mortality to be inescapable yet redeeming
- Investigates and interprets illness within the context of meaning
- Balances the spiritual with the physical and emotional
- Takes responsibility for health

**Spiritual Struggles/Needs/Issues/Opportunities may include:**

- Limited or absence of community/connectedness
- Fear/Denial
- Trust/Distrust
- Anger/Bitterness
- Conscience/Guilt/Shame
- Justice/Fairness
- Hope/Despair
- Isolation
- Security/Assurance
- Grace/Mercy
- Peace/Struggle/Coping/Inner Resources
- Helplessness
- Judgment/Testing
- Meaning of Existence(purpose/aimlessness)
- Forgiveness/Reconciliation
- Afterlife
- Meaning of Suffering (“Whys?”)
- Relationship with God
- Relationship to Transcendence
- Loss of Faith / Hope

## COMMON PATIENT SCENARIOS

### *Documentation of Individualized and Measurable S/C Goals and Outcomes*

#### **SCENARIO #1:**

***Spiritual Care Assessment:*** 85 year old woman with end stage dementia. Patient was mostly nonverbal during visit with spiritual care counselor (she uttered an occasional word or two which was difficult to understand). She communicated with her eyes and occasionally, smiled as chaplain provided tactile touch and words of encouragement. Chaplain noticed several religious items and symbols on patient's walls and bedside table. In particular, a crucifix was on the wall across from her bed. Chaplain recalls from reviewing patient's chart, that she had limited vision, therefore wouldn't be able to see the crucifix from such a distance. Also, patient immediately became less anxious when the chaplain sat near her and introduced self. Upon entering the room, the PAINAD scale was 2 and once patient was aware of chaplain's presence it decreased to 0.

After the initial visit with the patient, the chaplain received additional information from the patient's family, the facility staff, and the IHH team. As a result, the chaplain was better able to identify the significant life events and spiritual beliefs and values of this patient. According to family and facility staff, patient was very active in her Catholic faith and participated in the choir each week. Sacred hymns and being a part of the community was important to her and gave her much joy. She has been living in the SNF for 5 years and as a result, has not been able to participate in these activities. The chaplain was able to ***begin*** assessing for potential spiritual/religious struggle or angst the patient may be experiencing and unable to verbalize. It appears as though the patient may be experiencing some spiritual distress or lack of spiritual connection/community AEB her initial restlessness (pain symptoms were addressed). Once patient became aware of chaplain presence/support, she appeared to have less anxiety and in fact, seemed more peaceful. The spiritual care documentation of individualized needs, goals, interventions, and outcomes may look like this:

***Spiritual Needs/Issues:*** Patient unable to perform usual religious practices (i.e. church choir). Patient has decreased sense of connectedness with faith community. Patient unable to derive joy, strength, and meaning as in the past - her poor vision prevents her from enjoying her surroundings (i.e. crucifix at a distance from patient's bed). Family support is limited due to geography, although they are supportive when possible. Patient seems to struggle with feeling abandoned by God at times, per family. Questions about "where is God now?" may be causing her spiritual distress.

***Spiritual Care Goal (of patient/family):*** To increase sense of God's love, care, and presence. To restore a sense of community and connectedness with others.

***Spiritual Care Interventions:*** Chaplain will bring patient's crucifix closer to patient; provide validation of patient and family's feelings to normalize their struggles; provide music at bedside, i.e. tape playing sacred music while patient is alone and chaplain will sing familiar hymns to help reconnect to faith beliefs; words of encouragement and hope

## SAMPLE DOCUMENTATION OF OUTCOME-ORIENTED SPIRITUAL CARE

In this scenario, 70 year old woman has end stage cardiac. She is **conversant and engaged during the visit.**

### *Spiritual Care Assessment (Initial):*

#### *Spiritual Need/Issue:*

Patient continues to decline physically and reports anxiety r/t to the dying process and fear of going to hell. **Spiritual Care Goal:** Patient expressed interest in exploring her fears and would like to experience inner peace and God's acceptance.

**Spiritual Care Interventions:** Active and reflective listening to normalize fears and guilt associated with death/dying and existential suffering. Explored patient's faith history to help her see a connection between her religious upbringing and current spiritual struggle. Her image of a punitive God and rigid church teachings were discussed (patient desired this) Read prayers and scripture to patient pertaining to her fears and provided opportunity for patient to reflect and ponder. **Measurable Outcomes:** After several visits of developing trust with patient, she has become more accepting of spiritual care interventions. Patient is beginning to identify and explore her fears about the afterlife and the possibility that God is all-loving and compassionate, rather than judgmental and punitive. As a result, her anxiety seems to have lessened AEB: patient able to see humor in circumstances; she smiles frequently throughout visits; she verbalized underlying fears r/t beliefs and has requested that spiritual care counselor return to further explore her concerns. Spiritual care frequency will be 1xweek + 1prn for spiritual struggle.

## **SPIRITUAL ASSESSMENT**

Residents bring all their life experience with them when they come to the nursing home. As professionals, we can make helpful observations that can help care for the residence during their hospice care.

### **POSITIVE SPIRITUAL RESOURCES**

#### **Need for Meaning and Purpose in Life**

Expression that s/he has lived in accordance with his/her value system

Expresses desire to participate in religious rituals

Expresses hope in life after death (or peaceful acceptance of death as end of life)

Expresses hope in the future

Expresses hope in life after death

Expresses confidence in the health care team

Expresses feeling of beloved by others and God

Expresses feeling of forgiveness by others and God

Trust others/God with the outcome of a situation in which they have no control

Expresses love for others through actions

Seeks for good of others

Asks for information about their condition realistically

Uses time during illness constructively

Value their inner self more than their physical self

### **EXPRESSIONS OF SPRITUAL NEED**

Expresses that they have no reason to live

Questions the meaning in suffering and death

Expresses despair

Exhibits emotional detachment from self and peers

Jokes about life after death inappropriately

Worries about how the rest of their family will manage after their death

Expresses feelings of faith in God

Expresses fear of dependence

Does not call on other for help when they need it

Expresses feeling of lack of support by others

Behaves as the "should" by conforming to the behavior of a "good" person or patient

Expresses guilt feelings and fear of God's anger

Expresses anger with self or others

Expresses ambivalent feelings toward God

Expresses despondency during illness

Expresses resentment toward God

Expresses loss of value due to decreased abilities

Worries about the financial status of family and separation from family

Worries about separation from others through death

Express fear of loss of control

Is unable to do creative pursuits due to illness

Exhibits overly dependent behaviors

Expresses fear about how they will die

**Hospice patients have a need to give and receive love and most important need for hope.**

## THE SPIRITUAL HISTORY Assessment Tool

Maugans TA, MD. (1996) "The SPIRITual history." Arch Fam Med 5 (1): 11-16.

[http://www.eperc.mcw.edu/fastFact/ff\\_019.htm](http://www.eperc.mcw.edu/fastFact/ff_019.htm)

**Fast Fact and Concept #019. Taking a Spiritual History.** 2nd Edition. Author(s): Bruce Ambuel, PhD. Maugans (1997) presents a framework for taking a spiritual history; the interview below comes primarily from Maugans' article with some modification based upon the other sources cited.

### **S—spiritual belief system**

- \* Do you have a formal religious affiliation? Can you describe this?
- \* Do you have a spiritual life that is important to you?
- \* What is your clearest sense of the meaning of your life at this time?

### **P—personal spirituality**

- \* Describe the beliefs and practices of your religion that you personally accept.
- \* Describe those beliefs and practices that you do not accept or follow.
- \* In what ways is your spirituality/religion meaningful for you?
- \* How is your spirituality/religion important to you in daily life?

### **I—integration with a spiritual community**

- \* Do you belong to any religious or spiritual groups or communities?
- \* How do you participate in this group/community? What is your role?
- \* What importance does this group have for you?
- \* In what ways is this group a source of support for you?
- \* What types of support and help does or could this group provide for you in dealing with health issues?

### **R—ritualized practices and restrictions**

- \* What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, service, etc.)
- \* What lifestyle activities or practices does your religion encourage, discourage or forbid?
- \* What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?

### **I—implications for medical care**

- \* Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines?
- \* What aspects of your religion/spirituality would you like to keep in mind as I care for you?
- \* What knowledge or understanding would strengthen our relationship as physician and patient?
- \* Are there barriers to our relationship based upon religious or spiritual issues?
- \* Would you like to discuss religious or spiritual implications of health care?

### **T—terminal events planning**

- \* Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality?
- \* Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?
- \* Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?
- \* From what sources do you draw strength in order to cope with this illness?
- \* For what in your life do you still feel gratitude even though ill?
- \* When you are afraid or in pain, how do you find comfort?
- \* As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?



Pain is a complex subjective experience that involves both neurophysiologic and emotional aspects. Many individual factors can affect a person's experience of pain and subsequent response to treatment including their past experiences with pain, the meaning they assign to their current pain, and underlying mood disorders (e.g. anxiety, depression, anger). At times affective and cognitive dimensions of pain along with psychosocial and spiritual issues can produce an overwhelming amount of suffering. However, pain and suffering are not inextricably linked. That is, some patients with pain report no suffering.

Attending to suffering, by listening, and offering empathy is a critical non-pharmacologic intervention. Obtaining a spiritual history can help patients and their caregivers further understand and attend to the suffering aspects of pain.

**What is Suffering?**

A philosophical source of remarkable insights into personal suffering is exemplified in Victor Frankl's account of his internment in a Nazi concentration camp, *Man's Search for Meaning*. Frankl, a psychiatrist, maintains that physical discomfort and deprivation, no matter how extreme or brutal, do not cause suffering. The true root of suffering is loss of meaning and purpose in life, he says. Being free of physical suffering, he believes, is not enough to sustain a person, and he quotes the philosopher Friedrich Nietzsche to explain the power of meaning to triumph over physical suffering: "He who has a *why* to live, can bear almost any *how*." Pain and privation can be endured if it is for a purpose. Although each person's meaning is different, existence that is merely a burden and lacks a future with any direction or point produces the worst kind of suffering. Source: Byock, I. *Dying Well* pg 83

Obtaining a Spiritual History	
<b>S = Spiritual belief system</b>	Do you have a spiritual life that is important to you? Do you have a formal religious affiliation? What is your clearest sense of the meaning of your life at this time?
<b>P = Personal spirituality</b>	When you are afraid or in pain, how do you find comfort? Describe the beliefs and practices of your religion that you personally accept. In what ways is your spirituality/religion meaningful to you in your daily life?
<b>I = Integration with spiritual community</b>	Do you belong to any religious or spiritual groups? How do you participate in this group? In what ways is this group a source of support to you?
<b>R = Ritualized practices and restrictions</b>	What lifestyle activities or practices does your religion encourage, discourage, or forbid? What meaning do these practices hold for you? To what extent do you follow these practices?

<p><b>I = Implications for medical care</b></p>	<p>Would you like to discuss religious/spiritual implications of health care?          Are there specific elements of medical care that your beliefs/religion discourage/forbid?          Are there any persons you would like us to include in your spiritual care planning?</p>
<p><b>T = Terminal events planning</b></p>	<p>Are there any unresolved areas of your life at this point that you would like us to assist you with addressing?          Are there practices or rituals you would like available in the hospital or home?          For what in your life do you still feel gratitude even though you are in pain?</p>

Hints for conversations about suffering and faith:

- Let the patient set the agenda, you don't need to ask about fear, unless they open the door to it.
- Don't underestimate the power of silence. Sometimes the best support is a simply listening.
- A person generally isn't looking for advice, just someone to listen and affirm that fear, anger, sadness, etc are normal.

References:

- Byock I. Dying Well: The Prospect for Growth at the End of Life. Putnam, Riverhead, 1997.
- Cassell, E. J. Diagnose Suffering. Annals of Internal Medicine 1999;131(7):531-534.
- Paice JA. Managing psychological conditions in palliative care. AJN 2002;102(11):36-43.



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Intranet: More Fast Facts in UConnect under Clinical Guidelines/Pain Management Resources  
 Internet: Visit [www.uwhealth.org/pain](http://www.uwhealth.org/pain)

TABLE 3. SPIRITUAL CONCERNS

<i>Diagnoses (Primary)</i>	<i>Key feature from history</i>	<i>Example statements</i>
Existential concerns	Lack of meaning Questions meaning about one's own existence Concern about afterlife Questions the meaning of suffering Seeks spiritual assistance	"My life is meaningless." "I feel useless."
Abandonment by God or others	Lack of love, loneliness Not being remembered No sense of Relatedness	"God has abandoned me." "No one comes by anymore."
Anger at God or others	Displaces anger toward religious representatives Inability to forgive	"Why would God take my child . . . it's not fair."
Concerns about relationship with deity Conflicted or challenged belief systems	Desires closeness to God, deepening relationship Verbalizes inner conflicts or questions about beliefs or faith Conflicts between religious beliefs and recommended treatments Questions moral or ethical implications of therapeutic regimen Expresses concern with life/death or belief system	"I want to have a deeper relationship with God." "I am not sure if God is with me anymore."
Despair/Hopelessness	Hopelessness about future health, life Despair as absolute hopelessness No hope for value in life	"Life is being cut short." "There is nothing left for me to live for."
Grief/loss	The feeling and process associated with the loss of a person, health, relationship	"I miss my loved one so much."
Guilt/shame	Feeling that one has done something wrong or evil	"I wish I could run again." "I do not deserve to die pain-free."
Reconciliation	Feeling that one is bad or evil Need for forgiveness or reconciliation from self or others	"I need to be forgiven for what I did." "I would like my wife to forgive me."
Isolation	Separated from religious community or other	"Since moving to the assisted living I am not able to go to my church anymore." "I just can't pray anymore."
Religious-specific	Ritual needs Unable to perform usual religious practices	
Religious/spiritual struggle	Loss of faith or meaning Religious or spiritual beliefs or community not helping with coping	"What if all that I believe is not true."

overall treatment plan. Using the language consistent with practice in most health care settings, this includes identifying or diagnosing the spiritual problems/needs; identifying spiritual goals (if appropriate); and determining, implementing, and evaluating the appropriate spiritual interventions (Tables 3 and 4). Health care professionals involved in assessing and referring patients should identify spiritual issues or make spiritual diagnoses if applicable. Some spiritual diagnosis labels currently exist but these may be limited in scope (e.g., to patients with cancer) and also are not presently used for reimbursement. Thus a clinician may identify a spiritual issue or a patient's sources of strength or the clinician may identify a spiritual diagnosis. In general a spiritual issue becomes a diagnosis if the following criteria are met:

1. The spiritual issue leads to distress or suffering (e.g., lack of meaning, conflicted religious beliefs, inability to forgive).
2. The spiritual issue is the cause of a psychological or physical diagnosis such as depression, anxiety, or

acute or chronic pain (e.g., severe meaninglessness that leads to depression or suicidality, guilt that leads to chronic physical pain).

3. The spiritual issue is a secondary cause or affects the presenting psychological or physical diagnosis (e.g., hypertension is difficult to control because the patient refuses to take medications because of his or her religious beliefs).

If there is an interprofessional team involved then a board-certified chaplain, as the expert in spiritual care, provides the input and guidance as to the diagnosis and treatment plan with respect to spirituality. In situations where there is no interprofessional team, health care professionals identify the issues or make the diagnoses and develop the treatment plan. These clinicians are responsible for referring complex spiritual issues to a board-certified chaplain. For simple issues, such as a patient wanting to learn about yoga, meditation, or art or music therapy, the health care professional can make the appropriate referral or implement a course of action. For

TABLE 4. EXAMPLES OF SPIRITUAL HEALTH INTERVENTIONS

Therapeutic communication techniques	<ol style="list-style-type: none"> <li>1. Compassionate presence</li> <li>2. Reflective listening, query about important life events</li> <li>3. Support patient's sources of spiritual strength</li> <li>4. Open-ended questions to illicit feelings</li> <li>5. Inquiry about spiritual beliefs, values and practices</li> <li>6. Life review, listening to the patient's story</li> <li>7. Continued presence and follow-up</li> </ol>
Therapy	<ol style="list-style-type: none"> <li>8. Guided visualization for "meaningless pain"</li> <li>9. Progressive relaxation</li> <li>10. Breathing practice or contemplation</li> <li>11. Meaning-oriented therapy</li> <li>12. Referral to spiritual care provider as indicated</li> <li>13. Use of story telling</li> <li>14. Dignity-conserving therapy</li> </ol>
Self-care	<ol style="list-style-type: none"> <li>15. Massage</li> <li>16. Reconciliation with self or others</li> <li>17. Spiritual support groups</li> <li>18. Meditation</li> <li>19. Sacred/spiritual readings or rituals</li> <li>20. Yoga, tai chi</li> <li>21. Exercise</li> <li>22. Art therapy (music, art, dance)</li> <li>23. Journaling</li> </ol>

the more complex spiritual issues, referral to a board-certified chaplain or other spiritual care provider is critical. Use of decision tree algorithms may facilitate the care process. Figure 4 is an example of one such algorithm.

Several surveys have demonstrated that some patients would like to be able to pray with their physicians and nurses.<sup>45,46</sup> A survey conducted by Stanford University Medical Center, ABC News, and *USA Today* in 2005<sup>47</sup> reported that prayer is the second most commonly used method that hospitalized patients rely upon for pain control, after opioid analgesics. Astrow<sup>1</sup> and Lo<sup>48</sup> have developed guidelines for praying with patients that could be adapted *a priori*. Regardless, prayer requests from patients should be handled sensitively and compassionately.

Tables 5 and 6 are examples of how spiritual care can be incorporated into a treatment plan. These plans should include input from the interprofessional team and be updated on a regular basis based on appropriate follow-up and re-evaluation.

**Evaluation and follow-up**

NCP Guidelines<sup>21</sup> call for periodic reevaluation of the impact of spiritual/existential interventions and patient and family preferences. Any time a diagnosis of a spiritual nature is made or a need is identified, whether related to pain, nutrition or a psychosocial or spiritual distress, it is of utmost importance to determine the impact of the interventions and adjust the plan of care as needed.<sup>49</sup>

**Documentation**

Documenting the provision of spiritual care allows for communication about the intervention and the corresponding desired outcomes. Documentation should occur in the social history section of the intake history and physical of the patient's chart, as well as in the daily progress notes as applica-

ble. Documentation of the intervention showing its value and effectiveness is key to quality care and provides knowledge to other members of the interprofessional team who share in the care of the patient. Health care professionals could consider documenting spiritual issues as part of a comprehensive biopsychosocial-spiritual assessment and plan. Sound clinical judgment should govern how much detail is provided in the documentation. Private content or information offered in confidence should be documented only to the extent that it directly affects the patient's clinical care of patients and is critical for other members of the interprofessional team to know.

**Recommendations**

1. Screen and assess every patient's spiritual symptoms, values, and beliefs and integrate them into the plan of care.
2. All trained health care professionals should do spiritual screening and history-taking. These caregivers should also identify any spiritual diagnoses and develop a plan of care. Detailed assessment and complex diagnosis and treatment are the purview of the board-certified chaplains working with the interprofessional team as the spiritual care experts.
3. Currently available diagnostic labels (e.g., National Comprehensive Cancer Network [NCCN] Distress Management guidelines,<sup>50</sup> *Diagnostic and Statistical Manual [DSM]* code V62.89,<sup>51</sup> NANDA nursing diagnoses<sup>52</sup>) can be used, but further work is needed to develop more comprehensive diagnostic codes for spiritual problems.
4. Treatment plans should include but not be limited to:
  - a. Referral to chaplains, spiritual directors, pastoral counselors, and other spiritual care providers including clergy or faith-community healers for spiritual counseling

# Program Integrity Tools

Ethical/Moral Issues		
Problem/Issues Opportunities	Areas for Goal Development with Patient/Family	Suggested Intervention
Pain/Suffering	<ul style="list-style-type: none"> <li>• To be able to embrace the suffering.</li> <li>• To find hopefulness united with spiritual meaning.</li> <li>• To find meaning in suffering.</li> </ul>	<ul style="list-style-type: none"> <li>• Facilitate open expression of feelings.</li> <li>• Assist in finding the Divine in the midst of suffering.</li> <li>• Offer reassurance of Divine presence that allows patient to embrace both the suffering and its hopeful meaning.</li> </ul>
Religious Issues		
Problem/Issues Opportunities	Areas for Goal Development with Patient/Family	Suggested Intervention
Religious/Faith Affiliation	<ul style="list-style-type: none"> <li>• Reconcile beliefs/values with patient's needs from faith/religious community.</li> </ul>	<ul style="list-style-type: none"> <li>• Evaluate patient's religious needs.</li> <li>• Assess need for as liaison between patient/family and faith community, if needed.</li> <li>• Provide assistance in expressing faith outside of a faith community (If patient/family do not seek community connectedness).</li> </ul>
Faith Community Connectedness	<ul style="list-style-type: none"> <li>• To establish relationship with faith community.</li> </ul>	<ul style="list-style-type: none"> <li>• Evaluate patient's needs from a faith community.</li> <li>• Address issues of alienation as desire.</li> <li>• Act as a liaison with appropriate faith community.</li> </ul>
Relationship with Clergy	<ul style="list-style-type: none"> <li>• To establish/reestablish positive connection with clergy.</li> </ul>	<ul style="list-style-type: none"> <li>• Identify troubling issues/previous experience with clergy.</li> <li>• Facilitate positive clergy relationship with patient and family.</li> </ul>

## Spiritual Assessment

Does patient identify with community of faith?

Is patient able to identify what has nurtured or sustained them during previous illnesses/times of crisis?

Is patient able to identify what is important to them as they live out the rest of their life?

Is the patient able to identify what gives them hope and meaning?

Is patient able to identify significant life events/interests/activities that are sources of joy?

Is patient able to identify significant life events that are sources of sorrow?

Is patient able to identify significant relationships/connections, sources of support?

Does patient identify spiritual issues/concerns they wish to address?

Is there a spiritual leader currently involved with patient/family?

Does patient desire <sup>chaplain</sup> to contact their faith community/faith leader?

Interventions/resources appropriate for patient and/or family

Affirm beliefs/values/culture/heritage

Anointing/Catholic Sacrament of the Sick

Artistic/creative expression

Contact faith community/faith leader

Contact facility clergy

Planning funeral service

Prayer/guided imagery

Presence

Reading scripture/sacred texts/other readings

Reflective/active listening

Reminiscence/life review/legacy

Sacraments/rituals

Spiritual/emotional reflection

Theological reflection

Not assessed

Does patient exhibit signs of spiritual strength?

Identifies strong personal faith

Identifies meaning and purpose

Feels generally peaceful regarding death

Feels connected to/supported by family and/or friends

Does patient exhibit/identify signs of spiritual distress?

Struggling with elements of dying process

Struggling with what happens after death

Struggling with meaning and purpose

Struggling with unresolved feelings

Not assessed

# Hospice Insights

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*"You are richer today  
if you have laughed,  
given, comforted,  
healed, or forgiven."  
- Jack Bongioni, M.D.*

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## Alzheimer's Dementia and Hospice

Alzheimer's dementia is steadily increasing in the United States. Currently, about one percent of the nation's hospice programs serve people with dementia. Unless there is a cure, or preventative treatments, the number of people diagnosed with Alzheimer's will triple by the middle of this century (4 million > 14 million).

### Facts about Alzheimer's Dementia:

- ◆ Alzheimer's is a progressive and degenerative disease with an unknown cause.
- ◆ Currently, 10% of the population over age 65 has Alzheimer's and 50% of the population over age 85 has Alzheimer's.
- ◆ Alzheimer's is on the increase for middle aged people.
- ◆ Individuals diagnosed with Alzheimer's have a 3-20 year life span from the onset of the disease (the average survival rate is 8 years).
- ◆ Alzheimer's can only be accurately diagnosed by a brain autopsy.
- ◆ Alzheimer's is a disease with a gradual onset which progresses in the following pattern:
  - Short term memory loss,
  - Struggle to find words, finish thoughts, follow directions,
  - Forget names and faces of family and friends, and
  - Become fully dependent on a caregiver.

The primary focus of care for individuals who have a diagnosis of

Alzheimer's is to provide them with a safe and supportive environment. (Picard, D. (Fall 1997) A good mix waiting to happen – Alzheimer's is on the increase and hospice can play a role.

### Can Hospice Benefit an Individual with Alzheimer's and Other Dementias?

Often it is asked, "How can hospice benefit or impact an individual with Alzheimer's/dementia?" It is difficult to understand how it can until we look at one of the main goals of hospice and that is "enhancing the quality of life".

How hospice enhances the quality of life is not only a subjective observation, but can be objective and quantitative in many aspects. Clearly engaging hospice services to relieve physical pain and symptoms can have a measurable outcome: however, when hospice attempts to relieve the emotional, social, and spiritual suffering the evaluation becomes much more subjective. Everyone has a different opinion on the outcome or success of the hospice team.

Many positive outcomes have been noticed when hospice care has been provided to individuals who are "unaware of their surroundings". In an effort to comfort those with Alzheimer's and other types of dementia, the following are

### Basic End-Stage Indicators:

- ◆ Overall physical decline
- ◆ Life limiting condition
- ◆ Clinical progression of the disease as evidenced by
  - Multiple ER visits
  - Inpatient hospitalizations
  - Serial physician assessment
  - Laboratory studies
  - Radiologic or other studies
- ◆ Impaired nutritional status
  - Decrease in appetite; increase in wt loss
  - Serum albumin <2.5mg/dl (not to be used in isolation)
- ◆ Multiple co-morbidities
- ◆ Decline in functional status (ADLs)

### Specific Guidelines for determining Prognosis

#### End-Stage Dementia

- ◆ Patients with dementia must show all of the following characteristics
1. Stage seven or beyond according to the Functional Assessment Staging Scale (FAST).
  2. Unable to ambulate without assistance.
  3. Unable to dress without assistance.
  4. Unable to bathe without assistance.
  5. Urinary and fecal incontinence, intermittent or consistent.
  6. No meaningful verbal communication, stereotypical phrases only, or ability to speak is limited to six or fewer intelligible words.
  7. Patients must have one of the following within the past 12 months.
    - Aspiration pneumonia
    - Pyelonephritis or other upper urinary tract infection
    - Septicemia
    - Decubitus ulcers, multiple, stages 3-4
    - Fever, recurrent after antibiotics
    - Inability to maintain sufficient fluid and caloric intake with 10% weight loss during the previous six months or serum albumin <2.5 gm/dl.

## Alzheimer's Dementia (Cont.)

benefits we see at hospice:

- ◆ Recognizing each individual as someone with intensive physical and emotional needs **maintains the dignity** of that individual because care then center around the unique and fluctuating needs of each patient.
- ◆ Facilitating non-verbal communication during cares, providing calming stimuli, and exhibiting sensitivity to individuality are interventions that **promote the emotional security** of the individuals with Alzheimer's/Dementia.
- ◆ Sensory deprivation and social isolation are known factors which cause undesirable behaviors in individuals with Alzheimer's/Dementia, therefore, the presence of another human being, especially at the end of life, would **provide comfort** and have a tendency to **minimize undesirable behaviors**. There are some techniques that are very useful in addressing these aspects of care: Use a soft tone of voice; choose calming words; play relaxing music, including classical, new age, nature sounds, etc.; touch is very therapeutic, and the gift of presence is always welcomed.
- ◆ Hospice focuses on quality of life, not quantity of life. This is true for all individuals with a limited life expectancy. Experience indicates that a short visit (15-20 minutes) with an individual with Alzheimer's/dementia is extremely beneficial. We have been told by long-term care staff that a short visit by the hospice volunteer has calmed an otherwise agitated hospice patient for the whole day ~ one cannot over-rate the "gift of presence".
- ◆ Families of individuals with Alzheimer's/Dementia benefit knowing their loved ones have extra attention and care provided at the end of their lives. This knowledge **eases the family's burden** of being the sole care-givers outside of the long-term care staff.

It is easy to answer the question "Can hospice truly make a difference with the Alzheimer's/dementia patient?" **ABSOLUTELY!!** It is extremely important for all caregivers to keep focused on the needs of the patient and, in doing so, the answer to that question will always be **ABSOLUTELY!**

#### Reference:

Berkley, D., Brady, R., Brown, J., et al, 1988. Clinical management of Alzheimer's disease. Aspen Publishers, Inc., Rockville, Maryland.



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#### Mission Statement

*Hospice of the Twin Cities' mission is to enhance the quality of the lives of our patients and their families by providing respectful care based on maintaining dignity, alleviating physical, psychosocial, and spiritual suffering, advocating for fundamental rights, and affirming the sacred value of life.*

## Response and Recommendations from S/C Goals and Outcomes In-Service

August 2, 2010

As of July 1, 2010, each IHH Spiritual Care Preceptor and Counselor has been in-serviced by Suzanne Weiss, BCC (and Marcus Bell, Chaplain Preceptor) on ***Individualized and Measurable Goals and Outcomes for Spiritual Care***.

Below are the responses and recommendations from the collective group of SCC's regarding Part I (Reflective Questions for Self-Disclosure) and Part II (Goal Setting and Outcomes) of the in-service:

- Language/Terms/Verbiage for S/C Assessment needs to be understood across clinical disciplines. This can be explored further using the *NHPCO Guidelines for Spiritual Care in Hospice* and other resources.
- The reflective questions helped chaplains reflect and share their own personal hurts, struggles, fears, etc. We must be aware of our own issues and needs if we are to effectively care for others. Some insights which surfaced from this activity were:
  - ❖ We must "receive the lament" of our patients/families; each visit is new and we are to allow it to "unfold" with no agenda (It was however, stressed that it is important to have a flexible plan as we begin our visits). Our hospice patients experience daily and significant losses and limits; they feel a loss of sense of self and often wrestle with questions concerning identity: "I'm not me anymore...who am I now?"
  - ❖ How can we as spiritual care counselors, help the patient uphold his/her dignity? What does their loss/limitations/impending death mean to them? To their family/caregivers? We need to assist them in reframing their lives and relationships with God, others, and themselves. Journey with them as they explore/relearn their concept of God as it relates to their current struggles, i.e. "Who is God now?" Normalize their grief.
  - ❖ Again, Chaplains (and other disciplines) must recognize and explore their own fears about growing older and death and dying. Like our patients, we want to be heard. We want others (i.e. healthcare professionals) to recognize our inherent dignity and see "the whole person", not simply the disease.
- Spiritual Care vs. Religious or Pastoral Care was discussed. The chaplain's role of *building relationship* with their patients and families is far different from simply responding to their religious needs. Therefore, the spiritual assessment is an on-going and fluid process which happens over time as the patient/family begins to trust the chaplain.
- Hospice patients often ask these questions: "Does my life matter anymore?" "Why am I still here when I can't help anyone anymore?" "Am I still loved by God/others?" "Will others remember me and carry on my legacy, values, faith?" "Is God pleased with me and my life choices?" "What will the afterlife be like?"

Some Common Human Needs (Maslow's Hierarchy of Needs was referenced):

- ❖ Self-Determination/Autonomy - Life Closure Issues
- ❖ Effective Grieving
- ❖ Meaning and Purpose
- ❖ Relationships/Beliefs/Values/Traditions and Rituals
- ❖ Hope – even if basic i.e. “I hope I can see my granddaughter’s birth before I die”

Dying is a profound rite of passage, filled with changes, mystery, suffering, distress and defining new hopes. We are *sojourners* with our patients in the search for meaning, comfort, hope, and strength.

- If our patients are nonverbal and unable to effectively communicate, then there is the loss of communication for them, their family, etc. They are still significant as a human being and need us to advocate for them. Many of our patients experience great isolation simply due to their living situation in a SNF and benefit from our supportive visits.
- Quality of life issues are things we can try to meet, i.e. offer a drink of water, check if they are in pain/discomfort, cover them up if cold, etc. Even when a patient can't respond verbally, he/she often communicates by extending his/her hand to us, shedding a tear, nodding their head, or a flutter of an eye. Even small responses are significant and meaningful. In addition, moments of silence and reflection are *essential* at times and we need to realize that it's enough that I'm present...fully present and engaged with this precious person. Several chaplains shared instances where they noticed such responses while providing spiritual care to patients. One chaplain recalled how his patient “seemed frustrated with her physical limitations AEB a break in her thoughts and pronounced grimacing.” These can be documented in a way which demonstrates the effectiveness of our interventions.
- Life review which explores the joys, sorrows, and events of our patient's life provides us with information and insights to our patients. However, with our less verbal and/or dementia patients, we often need to speak with the patients' family/caregiver, facility staff and our IHH team to discover what their spiritual/religious issues/needs might be.
- Sometimes we need to allow our patients to experience spiritual pain/suffering in order for them to explore the root cause; explore possible reconciliation; move toward real healing and wholeness. “Pain and privation can be endured if it is for a