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Multidimensional Assessment and Management of Pain (Suffering) at the End of Life

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My Goals:

In this workshop, I hope that we might…

- Understand the importance of a biopsychosocial-spiritual model of care
- Why a multidimensional assessment of suffering by a skilled interprofessional team is needed to most effectively manage pain and suffering at end of life
- Explore strategies to enhance our delivery of pain and symptom management

My Working Assumptions

- That you want to provide the *best care possible* to those you serve
- That you see opportunities for your organization and service to do better regarding Advance Care Planning
- That you each have a clinical and leadership role in ensuring quality advance care planning

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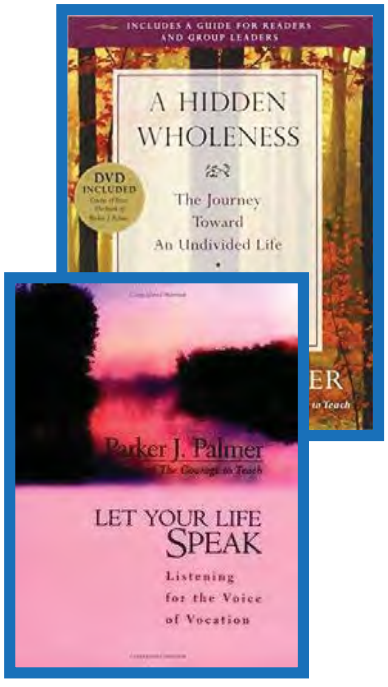
My Working Assumptions

- That you see this work as a *calling* (not just a *job*)
- That doing meaningful work is, well…meaningful
- That working in healthcare has offered you an invitation to consider your own mortality – that you recognize that you, too will die – and therefore understand that time is precious (and limited)



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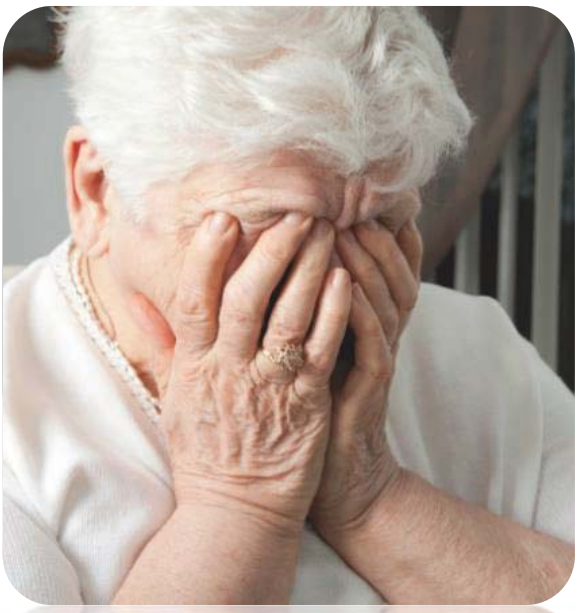
The Diagnosis of a Serious Illness Suddenly Changes *Everything*...

- It is an invitation to consider the possibility of our own mortality.
- This can be experienced as a "personal earthquake," reminding us that we are not in control, and the world isn't as predictable as we once believed.



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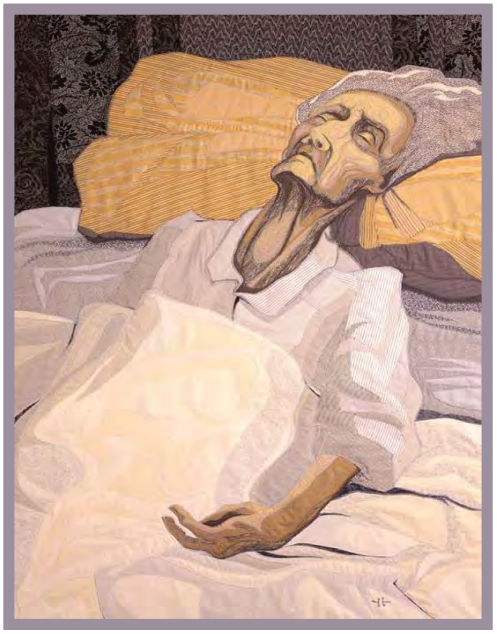
Perhaps the Essence of This Work is the Relief of Suffering and the Minimization of Regrets



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Courage Is Needed to Be Present to Suffering…

- Caring for those with a serious illness invites us to live our lives *as if* they matter, *now.*
- Embrace Vicarious Learning Opportunities: We are offered opportunities to see living and dying done by experts (observe what worked and what didn't and apply it in our own life).
- We are invited to face our fears of distance, disability, disfigurement, dependence and perhaps ultimately of death itself.

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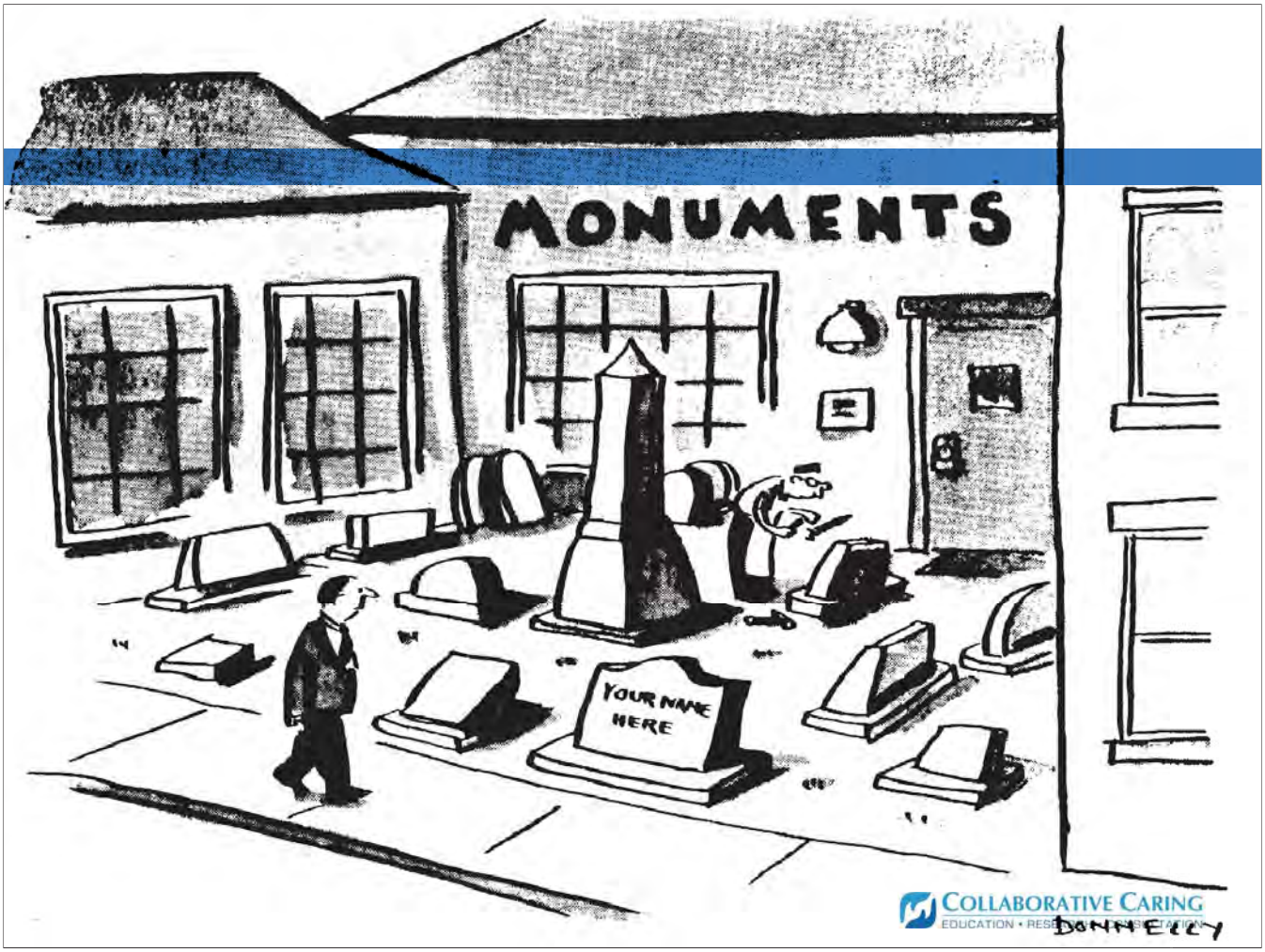

Health Care is at a Crossroads…

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I'm Convinced…

Our Current Health Care Delivery System is Broken…

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Large Body of Evidence

The majority of the seriously ill will interface with a fragmented system of healthcare that disproportionately limits access and resources & has demonstrated deficiencies in tailoring care to the most vulnerable.

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Growing Deficits in the Delivery of Care

- Unsustainable System of Healthcare
- Workforce Shortages
- Staff Dissatisfaction (Burnout, etc)
- Inequitable access to Quality Care
- Training Deficits for Delivery of Quality Care
- Increasing Need for Care as Population Ages
- Traditional Medical Model Leads to “Default” Treatment Decisions

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Systemic Challenges

- Until recently few healthcare professionals (including doctors & nurses) received adequate training in pain management.
- Busy clinics and short appointments mean that it's particularly difficult to find time to provide comprehensive information about pain management plan. Strategize regarding how best to address this…

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Our Goal ~
The Reliable Delivery of…

Quality, Competent, Compassionate, Culturally-Congruent, Person-Centered & Family-Focused Care

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Perhaps, A Way Forward… Palliative Care

- Interdisciplinary, Culturally Relevant, Evidence-Informed, Collaborative Practice.
- Goals:
  - Improve Function
  - Improve Quality of Life
  - Minimize Regret
  - Address the Multidimensional Aspects of Suffering

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Dr. Coluzzi's Rose Garden Challenge …You Know '*Enough*'

- Pain care can't be "optional" in quality practice
- Advocacy is an ethical mandate
- Professionalism requires a commitment to lifelong learning: You know where to look & how to learn more….
- We need to do what needs to be done ~ our patients are counting on us to figure it out!

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Palliative Care

- Collaborative, team approach
- Transdisciplinary perspective to address the multidimensional aspects of suffering (Goal: Minimize regrets)
- Embraces context: Engages family & community
- Encourages reflective practice

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Palliative Care Defined

- "The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies."

– www.nationalconsensusproject.org (2004)

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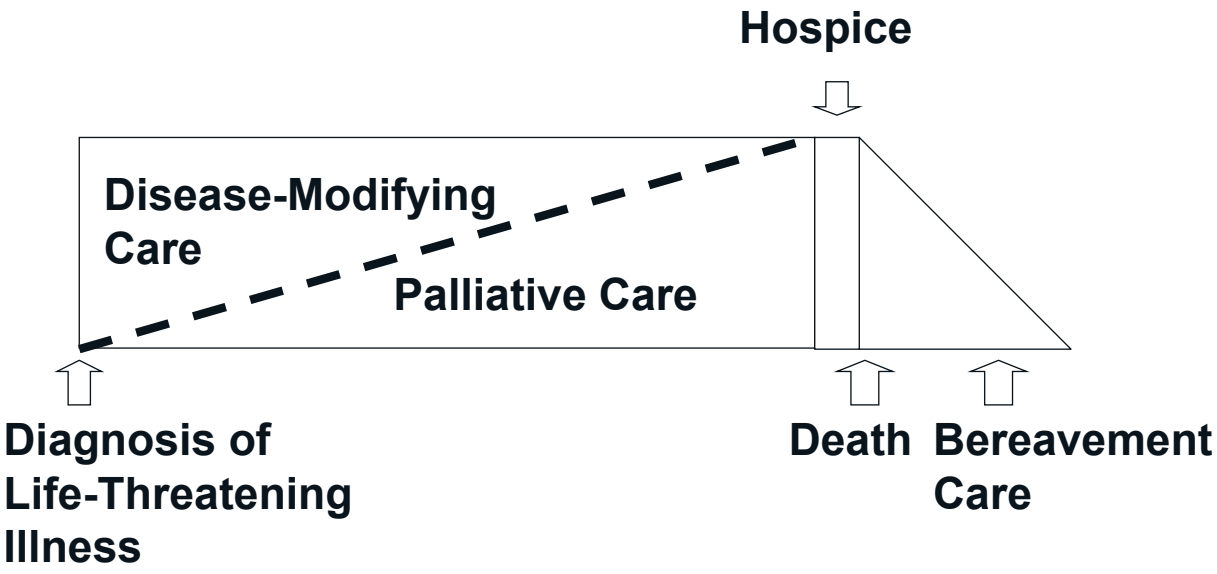
World Health Organization Model for Palliative Care



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National Consensus Project Guidelines to Quality Palliative Care

(2014)

- Integrates Biopsychosocial-Spiritual Care throughout recommendations
  - Pain & Symptom Management emphasized throughout
- Adopted in 2006 in their entirety by the National Quality Forum
  - Resulting in 38 Preferred Practices

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Quality Practice Guidelines
Domain 1: Structure of Care

- Plan of care is based upon a comprehensive interdisciplinary assessment of the patient and family.
- Based upon values, goals and needs of patient and family.
- Interdisciplinary team provides services consistent with the care plan.
- Recognizes the emotional impact on the team of providing this care.

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Quality Practice Guidelines
Domain 2: Physical Aspects of Care

- Pain, other symptoms and side effects are managed based upon the best available evidence, which is skillfully and systematically applied.
- Documentation of symptom assessment.
- Comprehensive approach to distress/suffering addressing the physical, psychological, social and spiritual aspects.
- Referrals are made when appropriate.

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Quality Practice Guidelines
Domain 3: Psychological Aspects

- Psychological and psychiatric issues are assessed and managed based upon the best available evidence which is skillfully and systematically applied.
- Communication is appropriate to developmental stage and cognitive capacity.
- A grief and bereavement program is available to patients and families, based on the assessed need for services.

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Quality Practice Guidelines
Domain 4: Social Aspects

- Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed in order to respond to these needs as effectively as possible.
- Assessment includes: family structure; relationships; cultural networks; social support; access to resources; school/work settings; intimacy/sexuality concerns; etc.

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Quality Practice Guidelines

Domain 5: Spiritual/Existential

- Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied.
- Regular, ongoing exploration about spiritual concerns are documented with use of a standardized instrument.
- Sensitivity of team to importance and diversity of spiritual beliefs/rituals.

Quality Practice Guidelines

Domain 6: Cultural Aspects

- The palliative care program assesses and attempts to meet the culture-specific needs of the patient and family.
- Team is respectful of cultural preferences in disclosure, truth-telling and decision-making.
- Care is respectful and accommodating of range of language; dietary; and ritual practices of patients and their families.

Quality Practice Guidelines
Domain 7: Care of the Imminently Dying

- Signs and symptoms of impending death are recognized and communicated, and care appropriate for this phase of illness is provided to patient and family.
- End-of-life concerns, hopes, fears and expectations are addressed openly and honestly in the context of social and cultural customs in a developmentally appropriate manner.
- Anticipatory guidance is offered regarding approaching death in developmentally-, age-, and culturally appropriate manner.

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Quality Practice Guidelines
Domain 8: Ethical and Legal

- The patient's goals, preferences and choices are respected within the limits of applicable state and federal law, and form the basis for the plan of care.
- Advance care planning encouraged.
- Special sensitivity to the needs of patients, minors, those with limited decision-making capacity, surrogate decision-makers.

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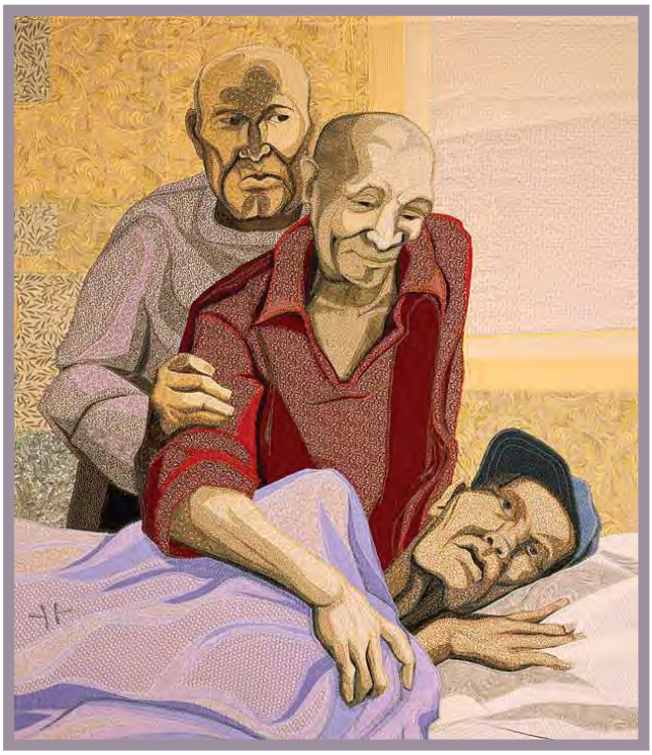
Culture & Spirituality



Key to Individualized Care!

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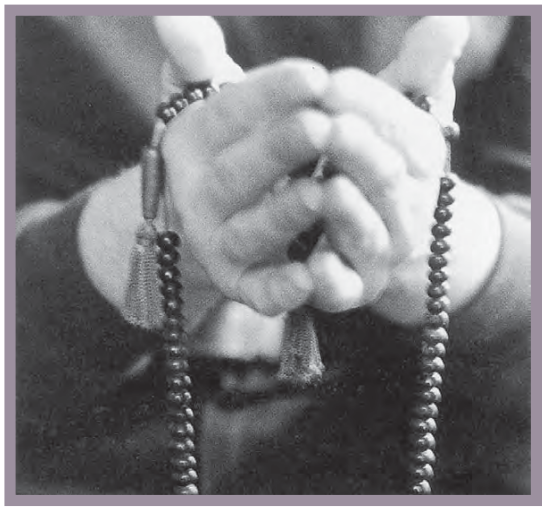
Bottom Line…

Assess, Don't Assume

Our Goal:

To achieve a more nuanced understanding of an individual's values & beliefs and learn how these influence care.



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Importance of Contextualized Care

"Person-in-the-Environment"

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Culture Provides the Lens Through Which We View Our Experiences

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Empathic Curiosity is Key

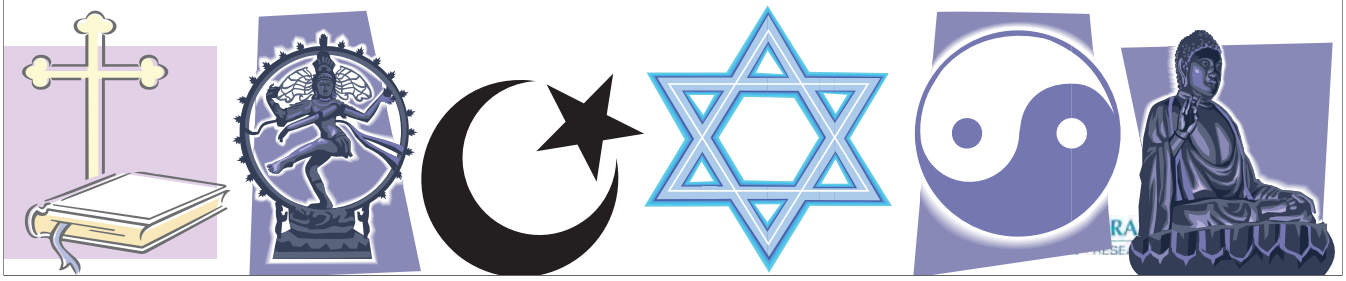
What's in the best interests of those we serve?

Key: Learn What Matters *Most*

- "Meaning of Life" for most centers upon interpersonal relationships
- Critical Goal: Minimize Regrets
- Importance of Listening: Learn *what matters most* to this particular patient at this particular time and what is interfering with their quality of life *now*.

Key Terms:

- **Religion -** Provide a "script" guiding behavior during times of transition and uncertainty (brings order from chaos)
- **Spirituality** is the broader "umbrella" term
- **Values** - Values are ideas that tell us what in life is considered important.
- **Artifacts** -Tangible items with symbolic importance that reflect the culture's values and norms.



Consensus Definition of Spirituality

*"**Spirituality** is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."*

Puchalski, et al. (2009). *Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference.* Journal of Palliative Medicine, *12*(10), 885-904.

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Quality Palliative Care *is* Individualized Care

- Patient's worldview may emphasize family welfare over individual needs.
- "Family" may be an extended kinship network.
- Roles within family may differ from your expectations.
- Family interventions may be most effective.

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"Cultural Competency"

- Awareness of diverse cultural values & norms and the technical needs to serve them
  - Need to know local communities (e.g. immigration issues)
  - Language issues: need for trained interpreter services
  - Need to be aware of cultural resources available to facilitate care
  - Diverse staff

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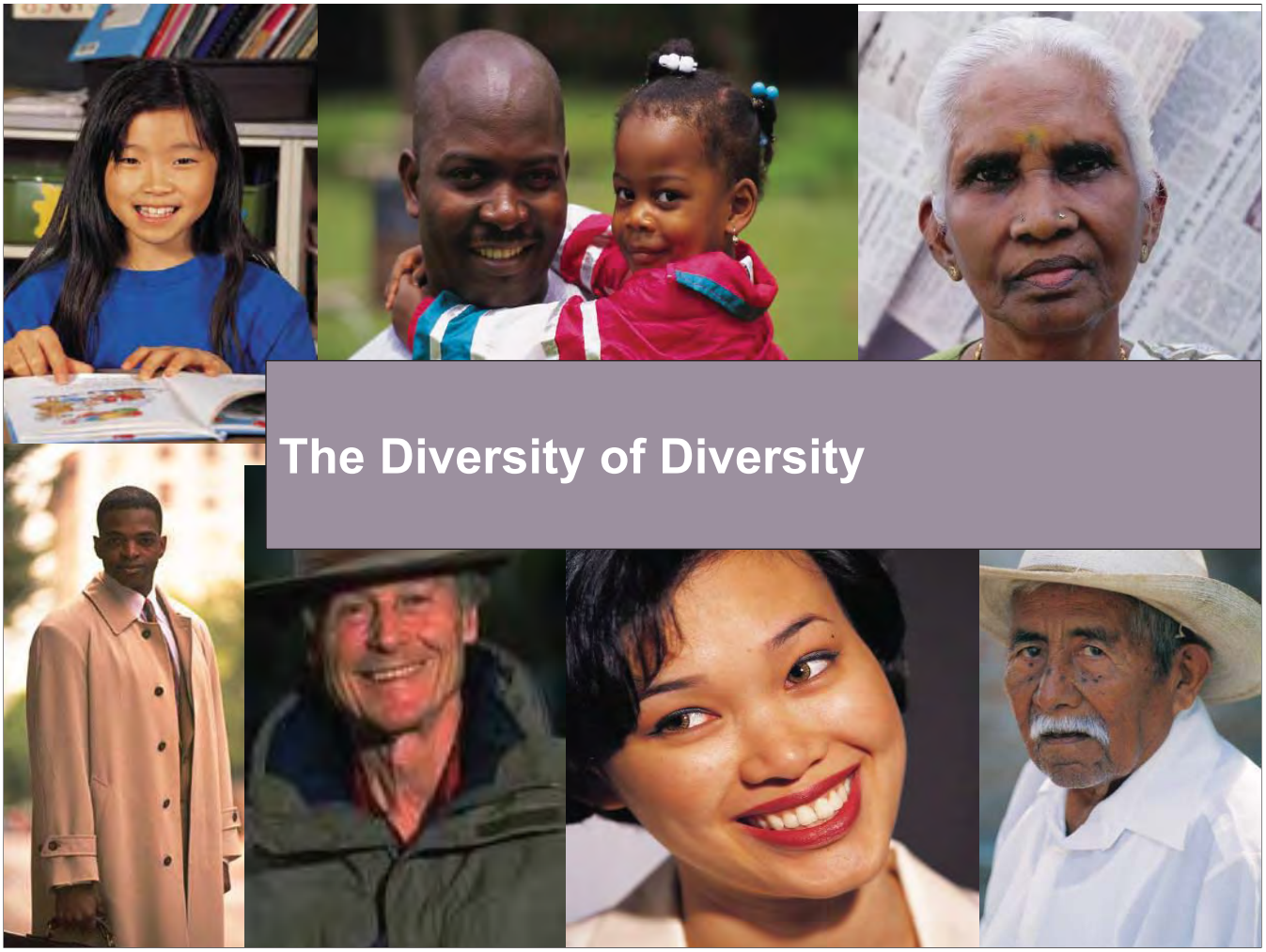

The Diversity of Diversity

- **Cultural Humility** (or sensitivity): awareness and respect for diversity

A commitment and active engagement in a **lifelong process** of:

- self-awareness
- self-reflection
- self critique

that individuals enter into on an ongoing basis with patients, communities, colleagues and with themselves.

Tervalon & Murray-Garcia. Cultural humility vs. cultural competence. *JI Health Care for the Poor and Underserved.* 1998

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Cultural Experience

- Patient Brings Expertise
  - We are each experts in our own culture and cultural history
- Requires
  - Beginner's Mind
- Goal
  - Levelling of the Patient-Provider Relationship

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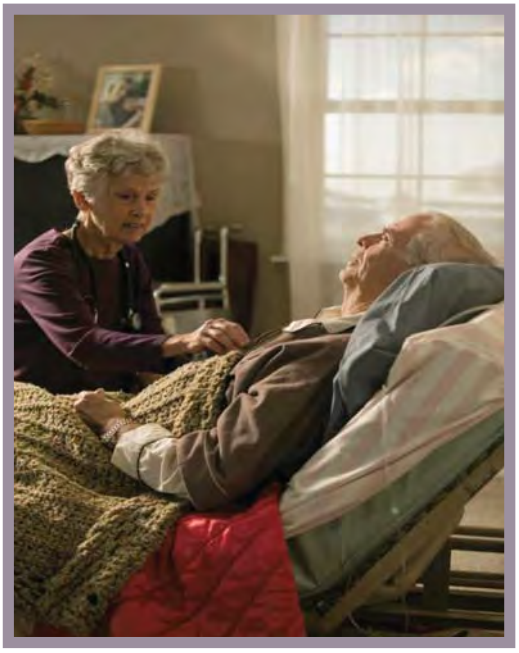
- **Cultural Dignity:** The goal of culturally appropriate, congruent, and nuanced care.



Dignity for the patient and family.

Dignity for the provider.

Dignity for the organization.

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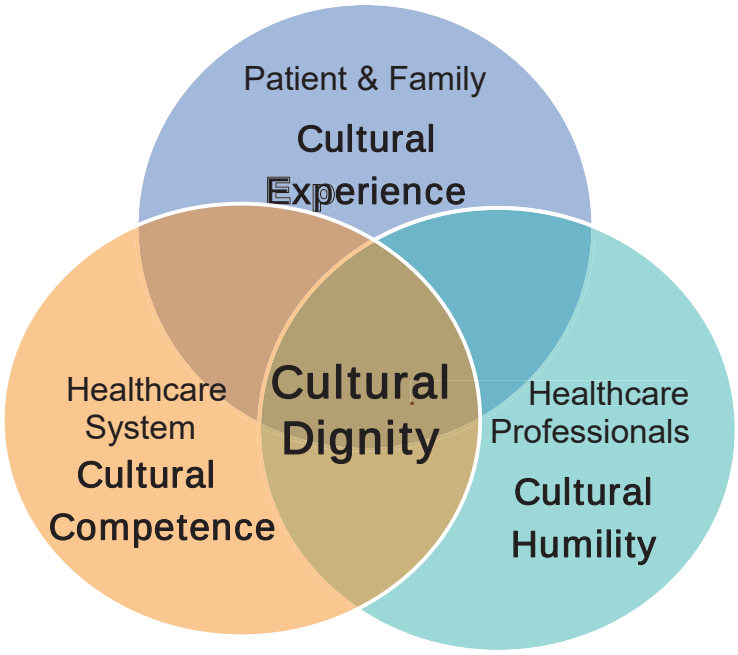
Multi-Culturalism Model



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Patient's Explanatory Model

- What
  - Do you call the problem?
  - Do you think the illness does?
  - Do you think is the natural course of the illness?
  - Do you fear?
- Why
  - Do you think this illness or problem has occurred?
- How
  - Do you think the sickness should be treated?
  - Do want us to help you?
- Who
  - Do you turn to for help?
  - Should be involved in decision making?

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Some Ways Variation Shows up at End of Life

- Truth Telling
- Who Makes Decision
- Putting Decisions in Writing
- Meaning of Pain
- Dying in the Home/Acceptance of Hospice
- Definition of a “Good Death”
- Rituals

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Exercise

- Which three aspects most influences your personal identity?
- Examples:
  - Gender
  - Age
  - Birth Order
  - Education
  - Sexual Orientation
  - Geography
  - Profession
  - Faith Preference
  - Generation
  - Socio-Economic Status
  - Parental Role
  - Immigration
  - Ethnicity
  - Political Affiliation
  - Marital Status

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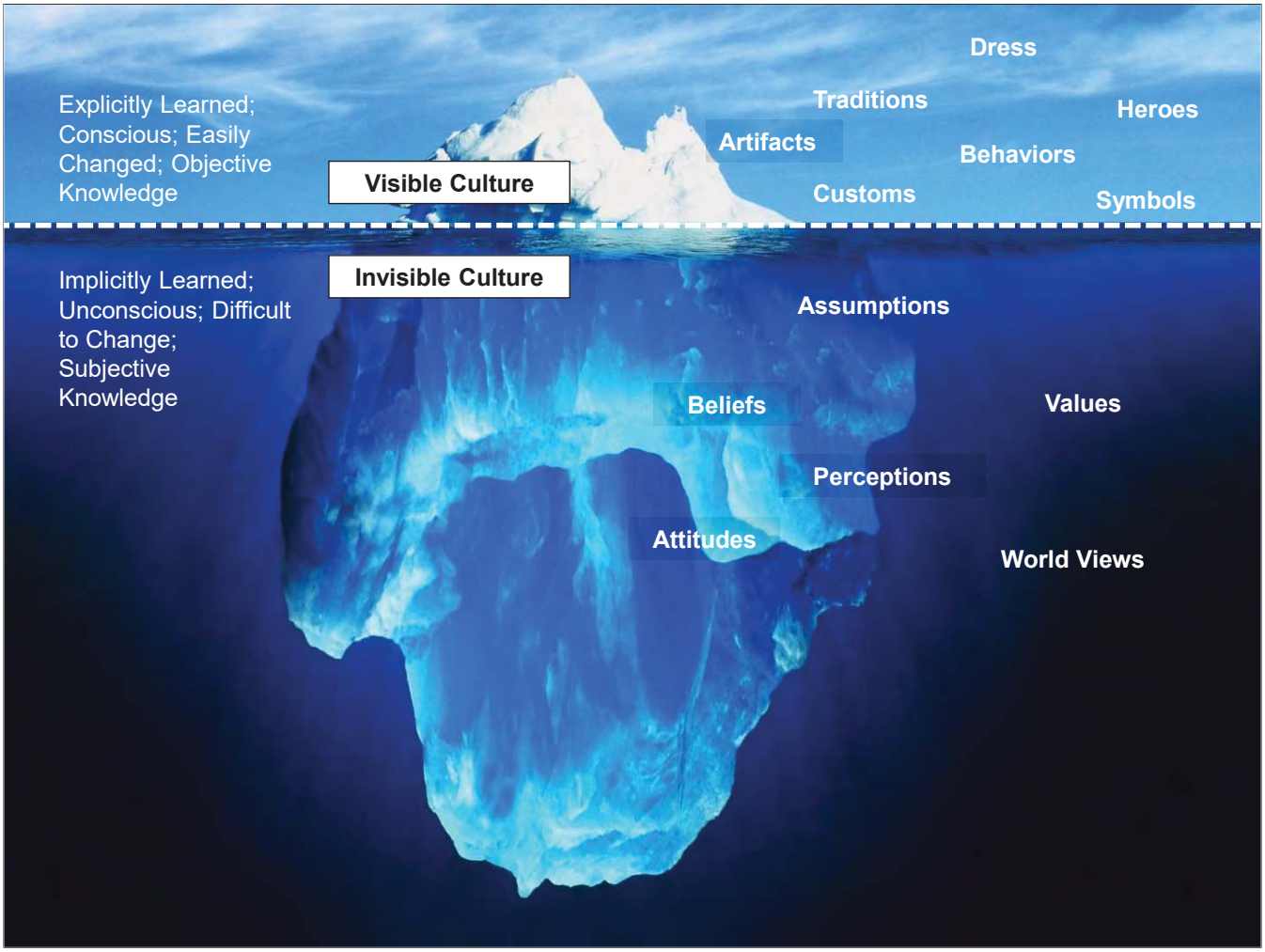
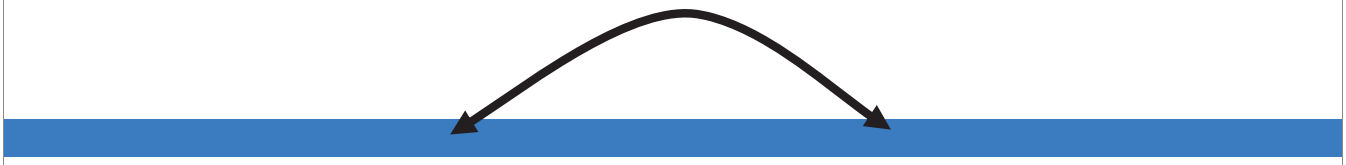
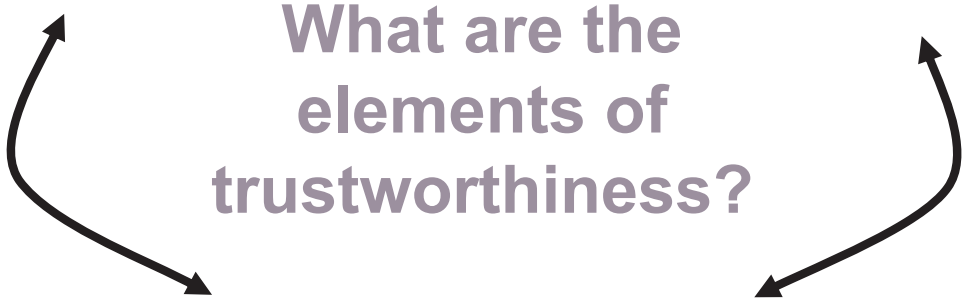




Entrusting
(Fiduciary implications)

Confidence
in Competence

What are the elements of trustworthiness?



Caring and Altruism

Cooper, David. Trust. *Journal of Medical Ethics* 1985, 11:92-93.

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One Size Doesn't Fit All…

***Dynamic Sizing**:* Our job is to assess and offer options and alternatives that are appropriate for this individual's *specific* needs to help them to reach their *specific* goals at this specific time…

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Common End-of-Life Concerns

- Impact of treatment options on quality of life
- Pain and symptom management
- Spiritual concerns regarding meaning of life
- Advance Directives
- DNR orders
- Impact of illness upon family (Burden - Protection Continuum)
- "Unfinished business"
- Discontinuation of life support
- Changes in treatment or prognosis

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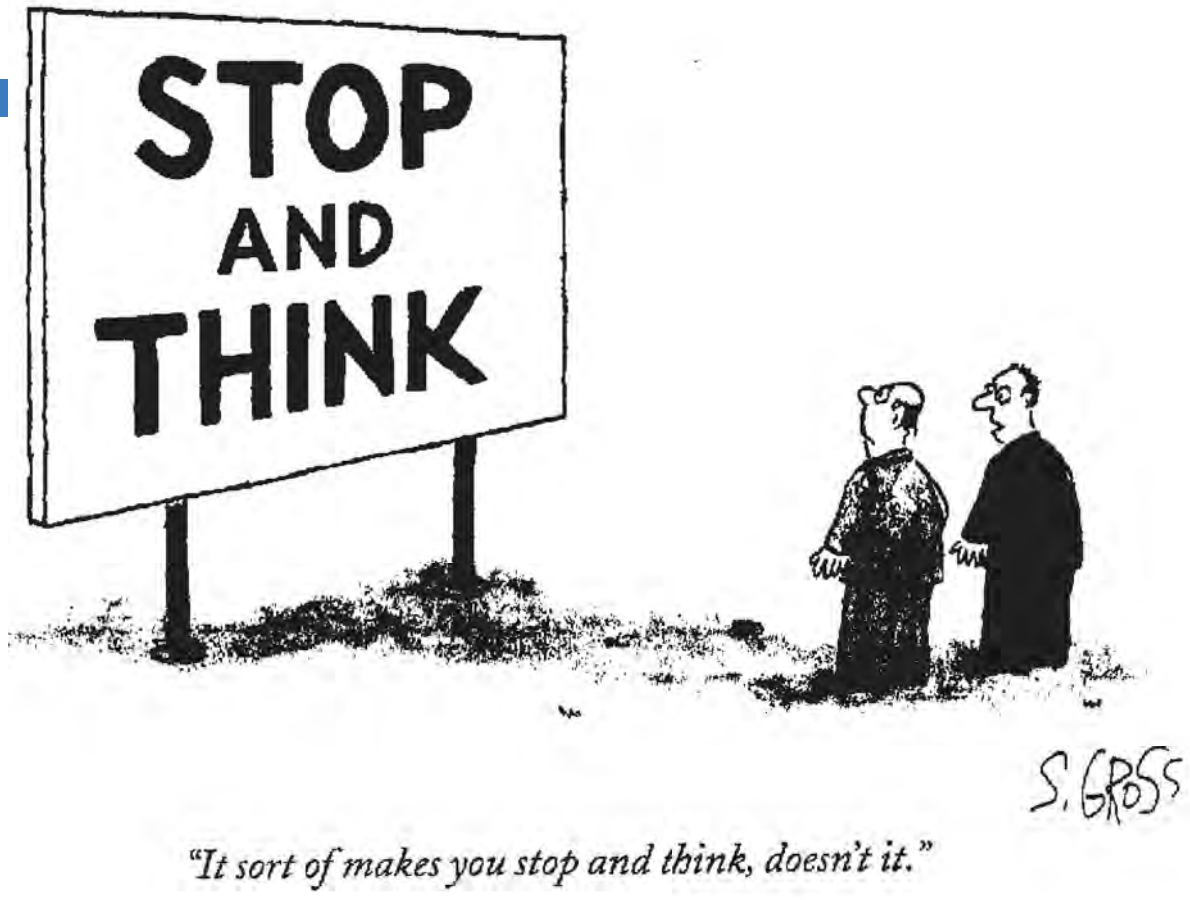
Key: Determine Patient's Values

- "What worries you the most about your future?"
- "What is most important for you to do, and what keeps you from doing it?"



"It sort of makes you stop and think, doesn't it."

Organizations Increasingly Recognize Importance of ACP

Yet few effectively ensure

that meaningful ACP conversations reliably occur… Why???

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"Prediction is Hard… Especially About the Future"

~ Yogi Berra

Prognostication is Difficult: There are Only Two Options

- Too Early
- Too Late

Trajectories of eventually fatal chronic illnesses.
Source: Lynn & Adamson, 2003

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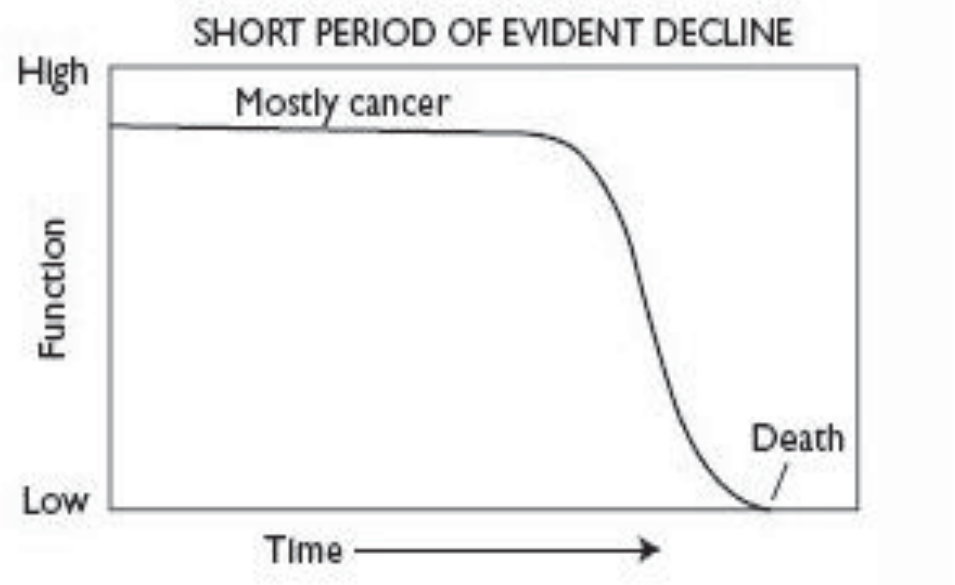
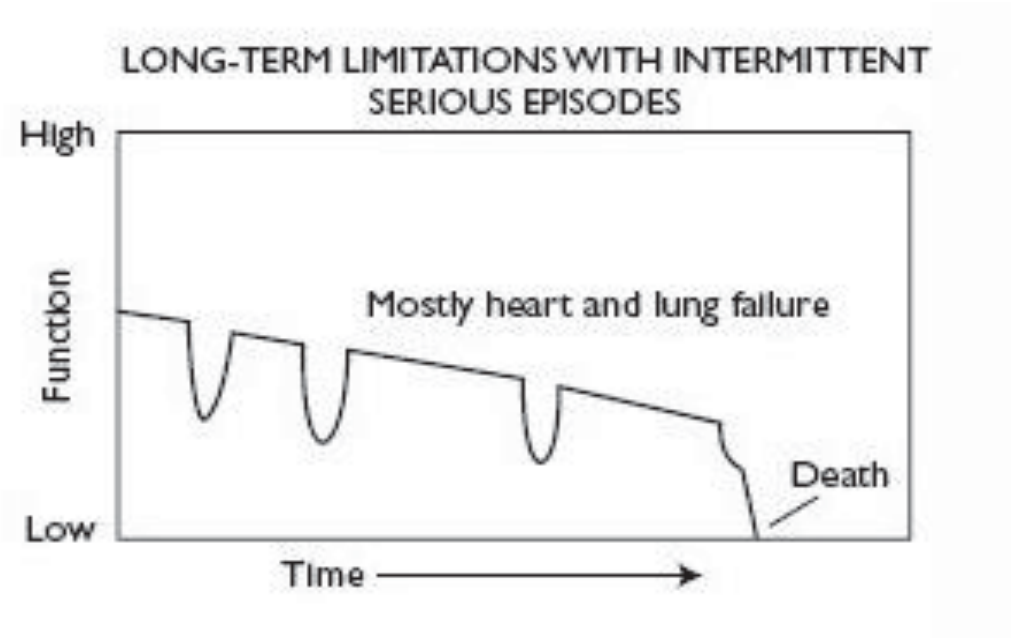


Trajectories of eventually fatal chronic illnesses. Source: Lynn & Adamson, 2003.



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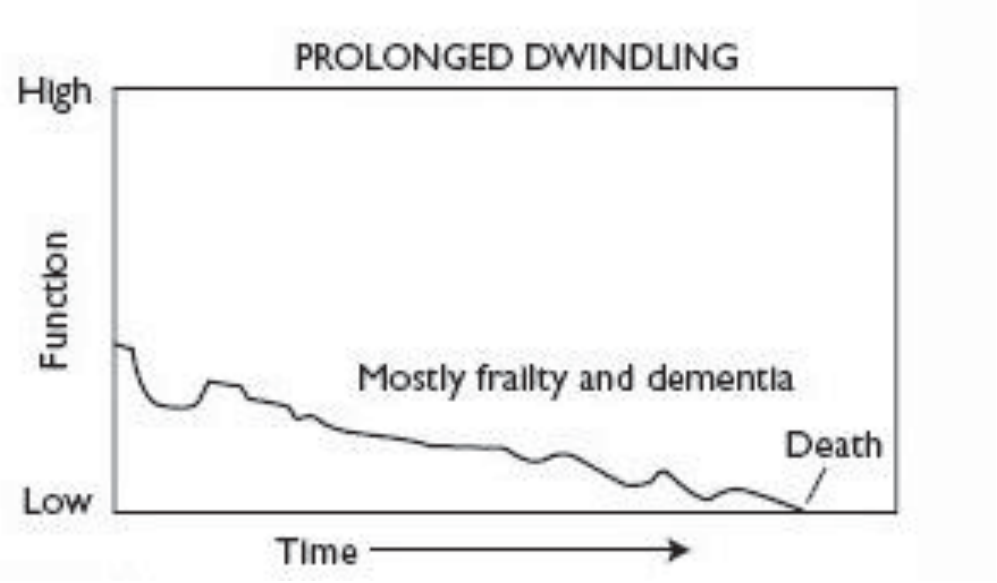

Trajectories of eventually fatal chronic illnesses. Source: Lynn & Adamson, 2003.

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CCCC Perspective on Advance Care Planning:
ACP Across the Continuum of Care

Age 18

Complete an Advance Directive

Update Advance Directive Periodically

Diagnosed with Serious or Chronic, Progressive Illness *(at any age)*

Provider Order Form and End of Life wishes.

Wishes Honored

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Advance Care Planning

ACP is a *process* (not an *event*)

That (ideally) evolves over a life span

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Strategic Preparation

- Advance preparation.
- Build a therapeutic relationship.
- Communicate clearly.
- Deal with patient and family reactions.
- Encourage and validate emotions.

Rabow, M.W., McPhee, S.J., WJM, 171, Oct. 1999

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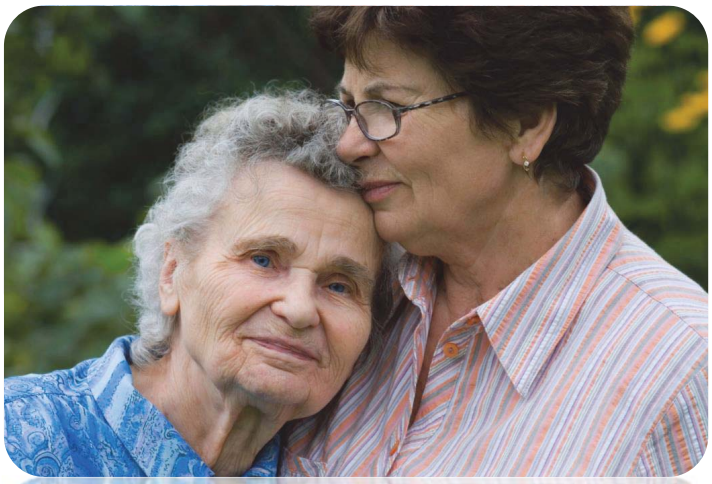
Determine Goals of Care, Values and Prioritization of Concerns...

Family Conference:

- Arrange to have significant others present.
- Ensure privacy.
- Allow sufficient time for meeting.
- Request services of an interdisciplinary team whenever possible.



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Goal for Advance Care Planning Conversations:

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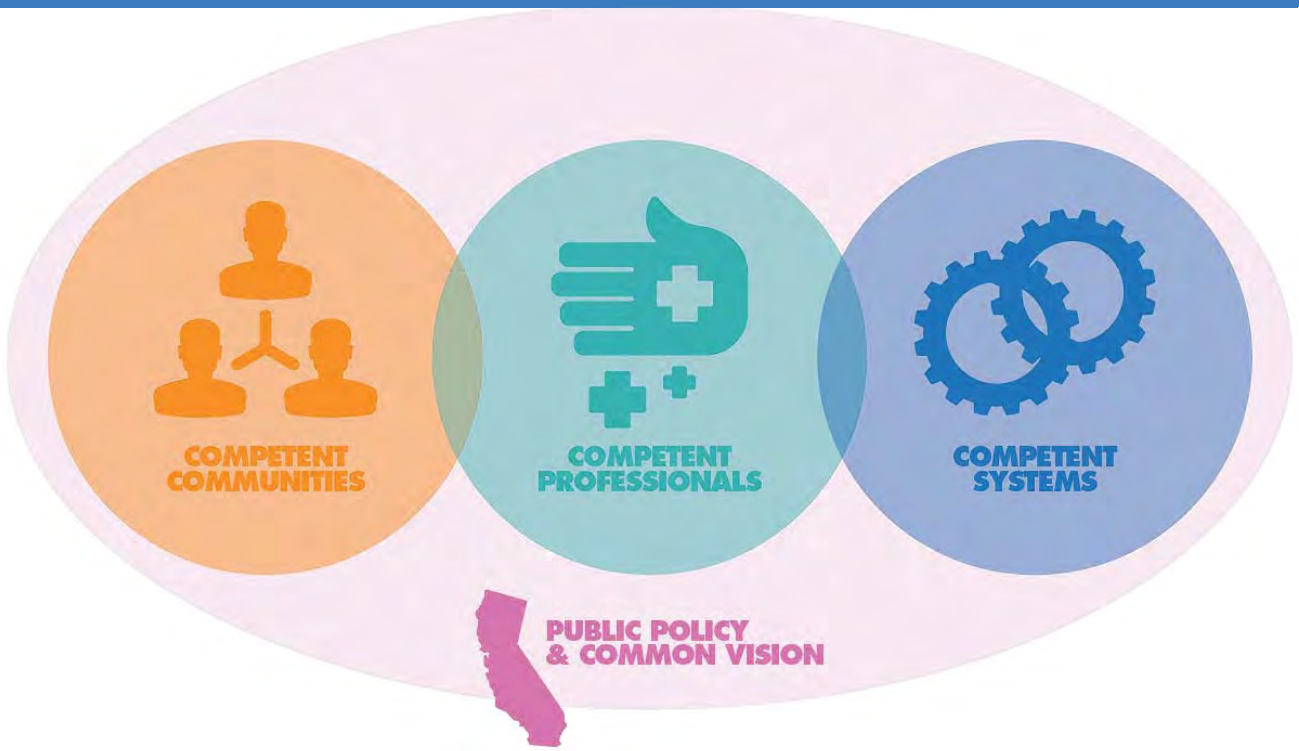
Coalition for Compassionate Care of California



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Advance Care Planning (ACP)

- The *process of communication* between a patient, family and clinicians to foster understanding about illness and prognosis to clarify treatment preferences, identify a surrogate, and guide goals for care in serious illness.
- Ideally results in:
  - Shared Goals of Care
  - Improved Informed Consent
  - Increased Patient Engagement

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Benefits of ACP

Meets the “Quadruple Aim” goals:

1. Patients are better satisfied
2. Populations better served
3. Wise use of healthcare dollars
4. Increased Provider satisfaction

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Critical Skills

- Self-Awareness
- Compassionate Presence
  - Capacity to “hold the space” and be a ”witness”
  - Put Individual Agenda Aside
- Verbal & Non-Verbal Communication
- Active Listening
  - Body, mind, heart
- Staying Open and Available
  - Open to discover
  - Available to help
- Emotional Intelligence/Cultural Intellegence

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Key: Active Listening

- Reframe questions
- Check to be sure that you are understanding the underlying message of concerns
- Allow ventilation of feelings
- Normalize concerns
- Confirm everyone’s understanding of the conversation & next steps

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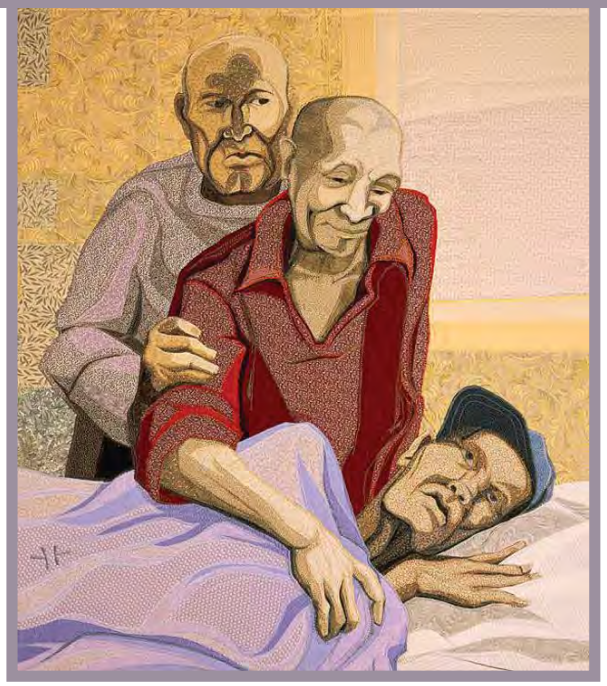
Reflection ~

- **Challenges?**
  - –Strategies to Address?
- **Inspiration?**
  - –Incentives?
  - –Motivations?



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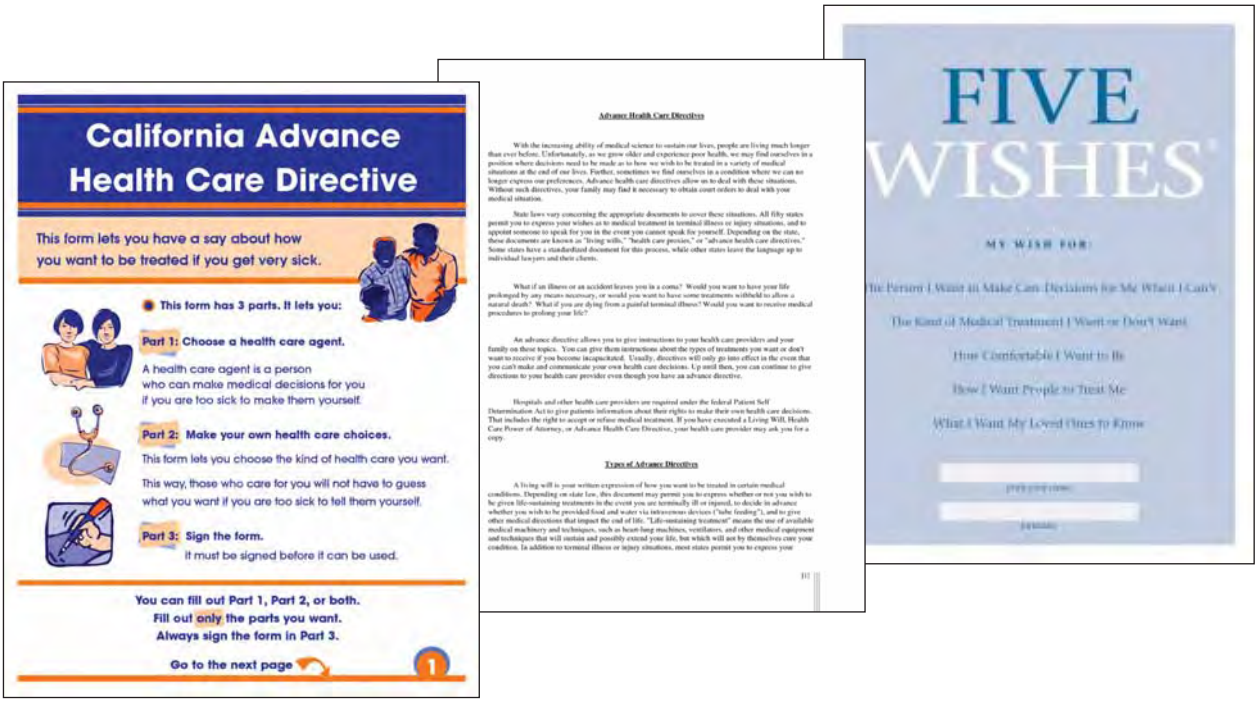
Advance Care Planning Documents



Images courtesy of the Coalition for Compassionate Care of California

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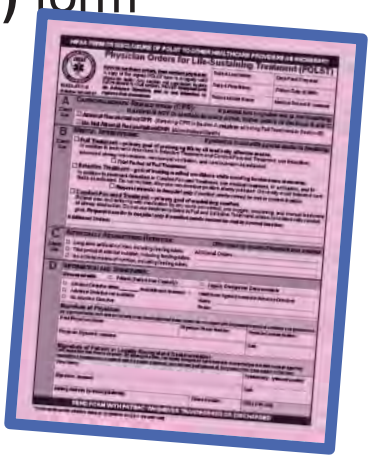
ACP Process:
When Illness or Age Are Advanced

For those who have short expected life-span, unstable disease or frailty, a **Physician Orders for Life-Sustaining Treatment (POLST)** form may be appropriate.



- Review wishes with family and providers
- Review Advance Directive
- Discuss life sustaining treatments
- Discuss and complete **the form**

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ACP Process

- Gather and share information
- Select a spokesperson
- Discuss wishes with agent, loved ones, MD
- Complete advance directive document
- Give copies to agent, loved ones, MD
- Periodically review and make any changes

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The Language You Use

Words have power.

- Help people choose language that focuses on outcomes and quality of life.
- Help them avoid non-specific terms that rely on interpretation (i.e. "Heroic Measures).

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Consider the Unintended Messages...

- *"If your heart stops, would you like for us to start it again?"*
- *"It's time that we consider withdrawing care."*
- *"Do you want us to do everything?"*
- *"There is nothing more that we can do."*

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Moral Distress

When our beliefs, values and actions aren't aligned…

- When our patient/family seeks a specific option but can't access their goal
- ***Regrets (and distress) may ensue…***

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Exercise: Reflection

Consider last time you encountered a situation where you felt your ethics/beliefs were compromised by another person's beliefs or behaviors ~

- How was this resolved?
- How do we address these differences?
- How are you supported at work when these differences manifest?

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Unrelieved Pain Has A Profound Impact Upon Quality of Life

- Energy and courage are required for optimal pain and symptom management, but unfortunately may be in short supply when facing a serious illness.
- Recommended to identify an advocate to assist as there's too much information to "go it alone" when managing pain

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Biopsychosocial-Spiritual Model of Pain

- Pain is a subjective, multidimensional experience comprised of physical sensations...
- Mediated by our (and our family's) interpretation of the situation...
- Within a social/cultural/spiritual context.

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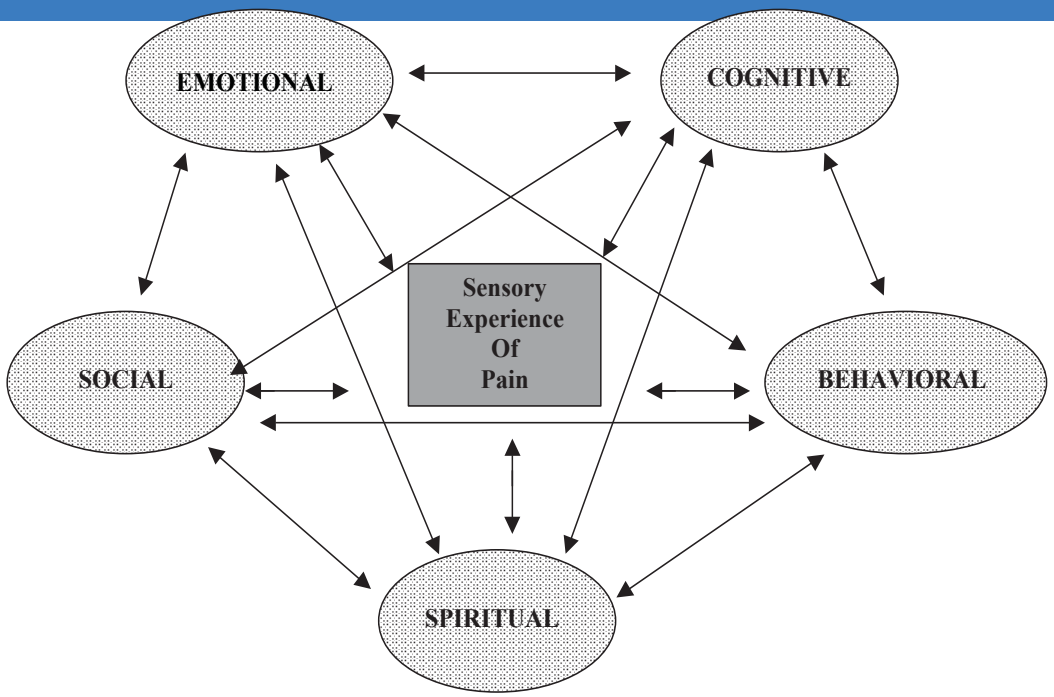
Psychosocial-Spiritual Model of Cancer-Related Pain



Otis-Green, Sherman, Perez, & Baird (Cancer Practice, May/June 2002)

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Pain Is Possible Throughout the Entire Illness Trajectory

- Treatment
- Remission
- Survivorship
- Recurrence
- Advanced illness
- Through end of life

Different Types of Pain:

Acute Pain
- Comes quickly and lasts only a short period of time.

Chronic Pain
- Lasts a long time (or all of the time).

Breakthrough Pain
- Intense pain that may be related to activity changes or stress (often especially challenging to manage due to unexpected occurrences).

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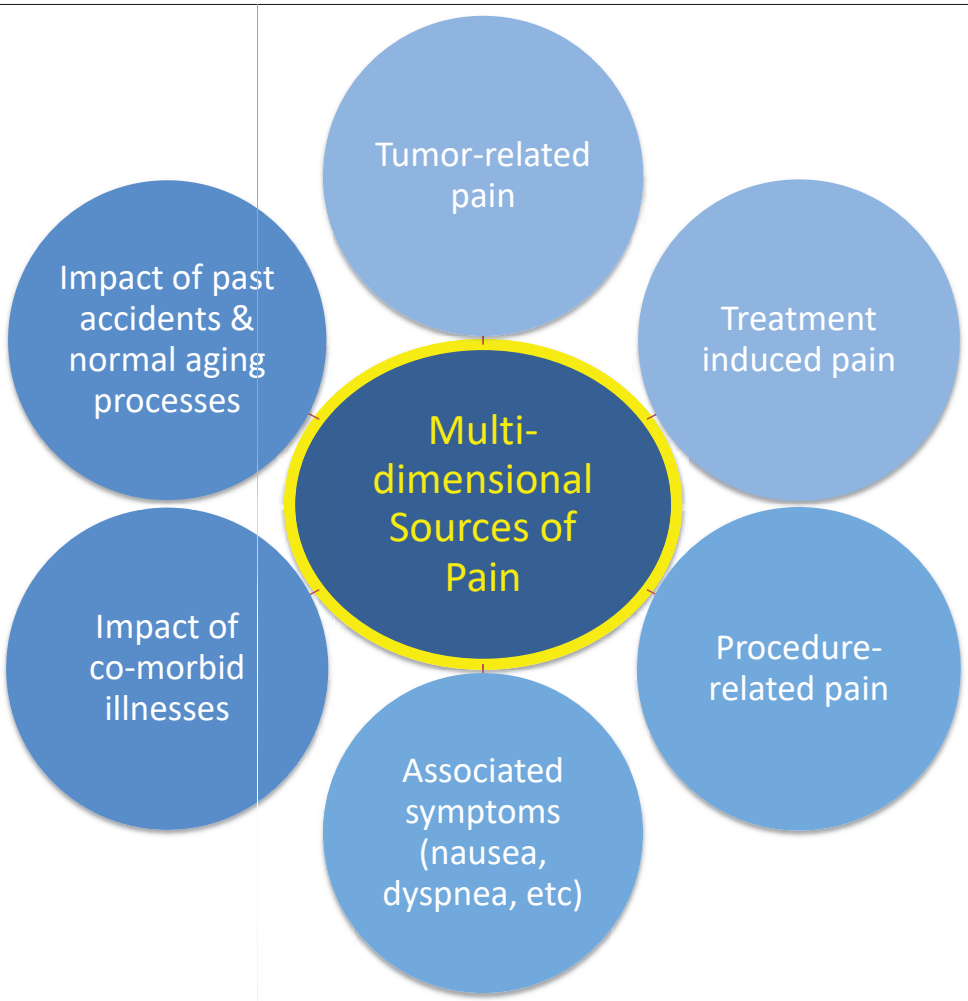
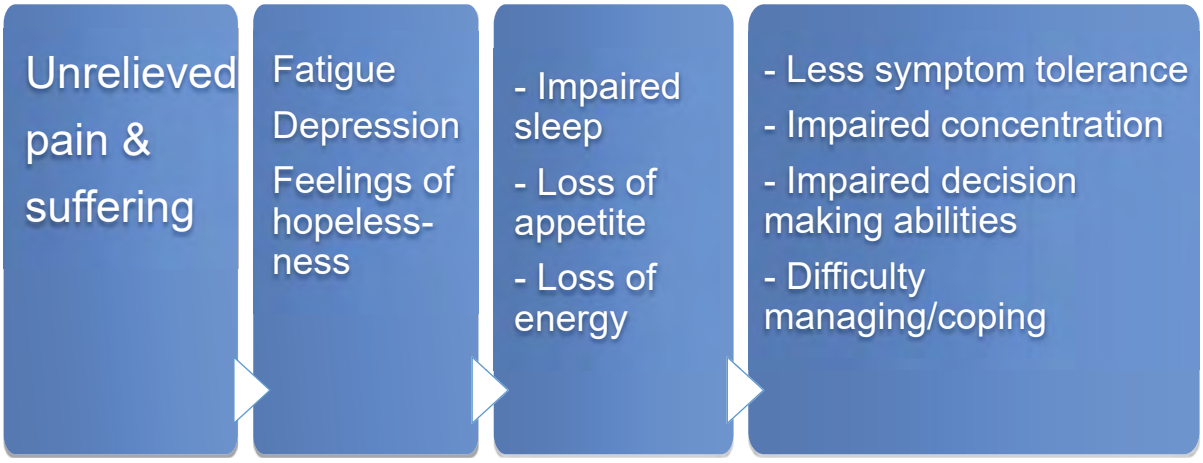


Differing Sources of Pain Require Differing Tactics for Relief

- For Example: the recommended chemotherapy for pancreatic cancer may worsen diabetic neuropathy impacting one's ability to continue to live independently.
- Lack of a reliable caregiver and limited resources may lead to escalating anxiety.
- Depression and existential concerns regarding future may lead to intense suffering, which in turn impacts pain tolerance.

"Symptom Clusters"

Downward Spiral: Suffering increases with unrelieved pain.



Pain Medications May Raise Concerns

- **Importance of Education**
  - Educate re: pain medications and pain management plan.
  - Anticipate "titration" challenges.
  - Ensure that there is a "bowel management strategy."
  - Explain the difference between: "addiction," "withdrawal," & "tolerance."
  - Be alert for myths and misconceptions

When Faced With Difficult Decision-Making:

- Provide realistic information regarding risks associated with each proposed intervention.
- Identify a reasonable trial period and explain the indicators of progress.
- Plan to periodically meet to review the changing situation.

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Stress Challenges Normal Coping Strategies

Anticipate:

- When in stress, our first response is to do more of what we normally do (unfortunately, this tends to get us more of what we usually got)…
- It's important to be open to trying new strategies when facing new situations…
  - C.O.P. E.

    C = Creativity

    O = Optimism

    P = Planning

    E = Expert Information

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The Importance of Communication

- We must help patient's communicate their symptoms
  - **Semantics Matter**: Some people deny "pain" but admit to "discomfort" or "ache"
  - Explore how it feels (mild, severe, stabbing, shooting, searing, throbbing, burning, dull, achy, cramping, tingling, etc).
  - And how long it lasts: (momentary, constant, intermittent).
- Assess for pain *patterns* (what "causes" the pain to be worse & what makes it better)?

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Communicating About Pain

- **Pain Scales**
  - *"On a scale of 0-10, with 0 as no pain and 10 as the worst pain you can imagine, what number would you rate your pain today?"*
- **Pain Diaries**
  - Record & rate when they feel discomfort (abdominal pain of "5" at awakening),
  - Record what you did to address it (taking medications, going for a walk, taking a nap),
  - Record how well this worked (pain went to a "3" after the warm bath).

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Assess For Special Challenges

- Insurance Questions
- Financial Limitations
- Transportation Concerns
- Fears and misunderstandings about medications
- Questions and concerns that patient or family members have regarding the symptom management plan

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Ensure that patients/families understand…

- How much medication to take? When? What if the pain gets worse?
- How long does the medicine last? When to expect relief? When can they take it again?
- Should they take this medicine with food or with liquids (is there a problem taking it with alcohol)?
- What are the common side-effects of this medicine? How should these be managed? (Should this medicine be taken with a stool softener & laxative?)

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Questions to Ask

- Explain concept of “titration” and how long it’s expected before reaching full effectiveness?
- If this is a medicine that their body may become tolerant to, how will we prevent withdrawal symptoms if we discontinue it?
- How will we monitor use of this medicine to minimize possible side-effects?

Ensure an Understanding…

- What to do for any “breakthrough” pain that they might have
- What other strategies (non-medical) may be successful for managing this type of pain
- How this plan helps achieve the patient’s overall goals of care
- Who they can call with questions after hours

Shared Responsibility: Minimize Regrets & Address Suffering

Embrace every opportunity to…

Make

Moments that Matter!

Difficult to do when in Pain…

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Goal

Balance of adequate pain control (with side-effect & symptom management) to allow your patients to focus upon what really matters!

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Explore Coping Strategies

- How have you attempted to ‘make sense’ of your situation?
- Role of spirituality?
- What types of things do you most enjoy?
  - How has pain impacted your ability to do these things?
- What’s a typical day like for you?
- How has this changed?
- What’s the most helpful strategy that you use to manage your pain/symptoms?

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Explore Coping Strategies

- What does worsening pain mean to you?
- What single thing is most troublesome for you of late?
- How have you faced other stressful events in your life? (*Past strengths can help them manage this situation as well)*
  - Child abuse?
  - Family violence?
  - Sexual abuse?
  - Accidents?
  - Military experiences?
  - Immigration?

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Explore Coping Strategies

- What types of medications have you used to help you cope?
  - Do you ever take them differently than prescribed?
- What other types of substances have you used?
  - Is your family worried about your use of these?

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Pain Can Nearly Always Be Relieved

- There are many different pain medications (non-opioids, non-steroidal anti-inflammatory drugs, opioids).
- There are many different routes to administer pain medications (orally, rectally, via “patch,” with “implantable pumps”, etc.).
- There are many additional medications (adjuvants) that maximize the effectiveness and lessen the side-effects of pain medications (anti-seizure & anti-depressant medications, etc).

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Explore Variety of Pain Relieving Strategies

- Radiation Therapy
- Neurosurgery &Tumor-Reduction Surgery
- Chemotherapy
- Acupuncture
- Bio-feedback
- Relaxation/Imagery Exercises
- Distraction
- Sleep
- Exercise & Physical Therapy
- Massage
- Yoga
- Use of Heat & Cold
- TENS (Transcutaneous Electric Nerve Stimulation)
- Animal-Assisted Therapies

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Perhaps…

"Life is painful...

suffering is optional."

Sylvia Boorstein

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Caregivers –

- Part of the *team* or *unit of care* ?
  - Discrepancy in assessment & report of pain
  - Data to be explored & understood
  - Cannot treat suffering of family by hastening the death of the patient
  - Tasks assigned to family members require clinical & ethical considerations

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Semantics Matter!

- "dysfunctional"
- "borderline"
- "drug seeking"
- "addicted / addict/ junkie/ clean & dirty"
- "*claims* to be in pain"
- "narcotics"
- Etc etc etc

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Attention to Language

- “there is nothing more we can do for you”
- “withdrawing & withholding care”
- “failed extubation; failed chemotherapy”
- “do you want everything done?”
- “life prolonging therapy”; “life support”
- “no more aggressive treatment”
- “there is no hope”
- “artificial feeding”

Communication is Key

- Everything is data (to be explored & understood)
- Redefine, reinforce & reframe
- Repeat using preferred phrases or words
- Ask questions
- “I need your help: Help me to understand…”

Pain Can Exist Anywhere Along the Illness Trajectory

- Acute Pain
- Breakthrough Pain
- Chronic Pain
- Intermittent Pain
- Treatment-Related Pain
- Pain While in Remission
- Pain May Signal Recurrence
- Pain May Worsen Through Advancing illness
- Pain May Lead to Recognition That Death is Imminent

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Prevalence & Incidence of Pain For Those With Cancer

Paice, (2010)

- Approximately 1/3 of persons actively receiving treatment for cancer
- Approximately 2/3 of persons with advanced malignant disease
- Approximately 3/4 of persons with advanced cancer admitted to the hospital

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Pain at End of Life

Paice, (2010)

- Incidence of pain increases as patients approach end of life
- Approximately 1/3 of persons report pain one week from death
- Pain is predominant symptom for referral to palliative care units: 70-90% of pain can be relieved

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Prevalence of Pain & Symptom Management Concerns

- Varies by Diagnosis
  - AIDS, Cancer, Diabetes…
- Varies by Treatment
  - Surgery, Radiation, Chemotherapy…
- Varies by Provider
  - Their Experience, Training, Sensitivity…
- Varies by Patient and Over Time…

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Those at Special Risk for Under-Treatment of Pain

Paice, (2010)

- Those who are Older
- Those who are Younger
- Those who are Female
- Non-English Patients
- Low-Literacy Patients
- Patients of Color

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Barriers to Pain & Symptom Management

Paice, (2010)

- Setting Barriers
  - Reimbursement
  - Staffing
  - Regulatory Environment
  - Media
  - Access
  - Prioritization

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Barriers to Pain & Symptom Management

Paice, (2010)

- Patient/Family Barriers
  - Reluctance to Report Pain
  - Concerns about Side-Effects, Diversion, Addiction
  - Desire to be a “Good Patient”
  - Fear that Increasing Pain = Worsening Disease

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Barriers to Pain Management: Caregiver Perceptions

Parker Oliver (2008)

- Coded “Pain Talk” during IDT Meetings –
  - Majority Focused upon Physical Pain, then Psychological and Spiritual and no discussion of Social Elements of Pain
- Caregivers (N=30) voiced overwhelming agreement with the statement:
  - “I’m afraid of doing something wrong when I give pain medication.”

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Social Work Role in Hospice Pain Management: A National Survey

Parker Oliver (2009)

- SWs report spending more than 20% of their time on pain issues, but feel more time is needed in this area
- Barriers to meeting this need are:
  - Lack tools to address caregiver concerns related to pain management
  - Lack time to devote to this work
  - Lack training to improve interdisciplinary collaboration

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Influence of cultural beliefs on pain management...

- Communication conflicts: Desire to “protect” patient from seriousness of condition and the implications to obtaining truly “informed” consent.
- Ethical challenges regarding differing belief systems.
- Extended family support systems often challenge medical center resources.

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Impact of Gender

- Are there differences in health care provider's perceptions?
  - Sensitivity to pain
  - Tolerance for pain
  - Validity of self reports
  - Objective, biological facts more credible

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Bottom Line…Pain Management Matters!

- Unrelieved Pain Impacts Treatment Options and May Lessen Length of Life
- Unrelieved Pain Impacts Quality of Life
- Unrelieved Pain Limits Function
- Unrelieved Pain Increases Hospitalizations and Costs of Care
- Unrelieved Pain Increases Suffering of Caregivers and Impacts Bereavement
- Unrelieved Pain Is Our Responsibility

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The Pain Imperative: *Comprehensive Biopsychosocial-Spiritual Pain Assessment*

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Assessments are Interventions & Assessments Invites Education

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From PLISSIT to Ex-PLISSIT*

- P = Permission
- LI = Limited Information
- SS = Specific Suggestions
- IT = Intensive Therapy

(Jack Annon, "Behavioral Treatment of Sexual Problems", 2 vols., Harper & Row - Medical Department, 1976;

* Taylor & Davis, 2004

http://www.springerlink.com/content/m0051230421x7835)

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Communication Tips

- Assist patient/family in communicating with healthcare team (education)
- "Help us to help you"
- Distinguish between "complaints" and "feedback"
- Look for patterns/associations
- Address "misunderstandings"
  - "Many people in this situation are concerned about…"

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Pain Management Presents Educational Challenges

Remember: As anxiety goes up – retention goes down – Plan to repeat information regarding new & potentially challenging concepts:

- Dose Titration
- Intermittent/Chronic/Acute
- Nuances & Complexities of Treatment Regime
- Symptom Clusters

Unique Aspects of Cancer Pain

- Pain tells us to *do something differently.*
- Cancer-related pain: On-going management for on-going insult (vs. “PRN” dosing with “hills & valleys”)

Comprehensive Bio-Psychosocial-Spiritual Pain Assessment

- Assess the total pain (suffering) experience (physical, social, economic, cognitive, emotional, spiritual/existential)
- Guide patient to prioritize areas of relative suffering *("What bothers you the most about this experience…?")*
- Assess and re-assess, don't assume!

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Location

- Localized vs. generalized / diffuse
- Superficial / deep
- Radiating /spreads to / extends to / travels to…
- Right-sided chest pain
- Abdominal cramps / gastric pain
- Chest tightness

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Quality (Pain Description)

- Aching
- Biting
- Burning
- Colicky / crampy
- Cutting
- Dull
- Gripping
- Knife-like / stabbing
- Mild
- Numbing
- Piercing
- Pinching
- Sharp
- Shooting
- Sore
- Spasmodic
- Squeezing
- Tearing
- Tender
- Throbbing
- Tingling sensation

Intensity

- Mild
- Moderate
- Severe
- Intense
- Agonizing
- Excruciating
- Discomforting
- Distressing
- Penetrating
- Suffocating
- Violent

Pattern / Duration / Frequency

- **Came on slowly /suddenly**
- **Acute / chronic**
- **Persistent; stubborn**
- **Continuous; steady; constant**
- **Rhythmic; periodic; intermittent**
- **Brief; momentary; transient**
- **Sudden intense pain followed by…**
- **Pain that comes and goes**
- **Severe cramps that wax and wane**
- **Intermittent, throbbing sensation**
- **Chest pain that occurs after exertion**
- **Recurrent episodes of pelvic pain**
- **Repeated episodes of extreme pain**
- **Episode lasted...**
- **Between one and three episodes per day**

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Moderating Factors

- Relieved by bending forward
- Intensified when eating and chewing
- Subsided after bowel movement
- Alleviated by; eased by
- When I lie down or sit down, the pain is worse.
- Made worse/aggravated by
- Triggered by fatty food
- Abdominal pain relieved by antacids
- Exacerbated by cold temperature
- Exacerbated by activity
- Aggravated on deep breathing
- Ameliorated by walking

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Associated Symptoms

- Accompanied by fever, chills and a cough
- Associated with weakness
- Accompanied by numbness in the arms and extreme fatigue

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Tool Selection: How Do We Choose?

- Research Rigor
- Clinically Useful
- Meets Regulatory Requirements
- Appropriate Developmental & Literacy Levels
- Available in Necessary Languages
- Inherited (Familiar Comfort Level: We always do what we've always done)

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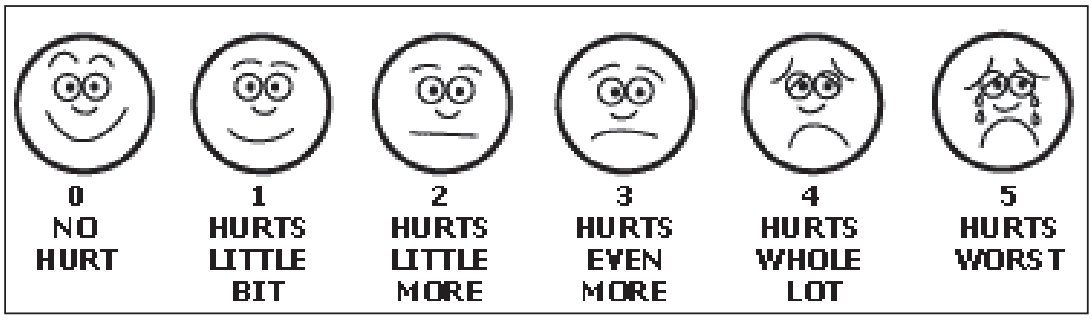
Palliative Performance Scale (PPSv2)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

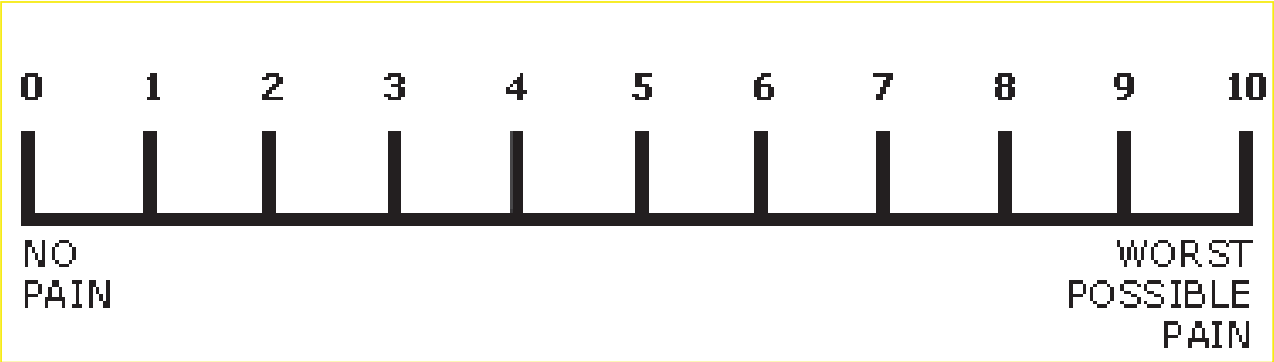
Visual Pain Scales



The Wong-Baker Faces Pain Rating Scale

Wong et al, (2001)

Numerical Pain Scale



McCaffery, (1999)

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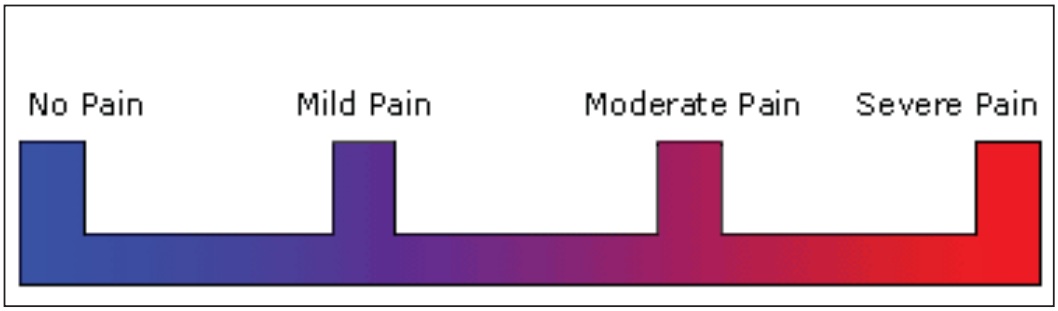
Verbal Pain Scale



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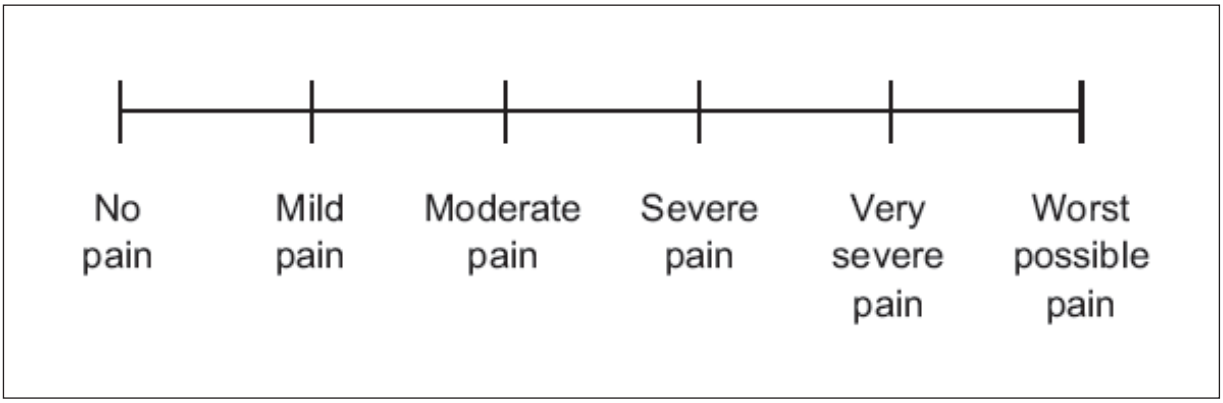
Descriptive Pain Intensity Scale



Agency for Healthcare Research & Quality, (1992)

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Initial Pain Assessment Tool

McCaffrey & Pasero (1999)

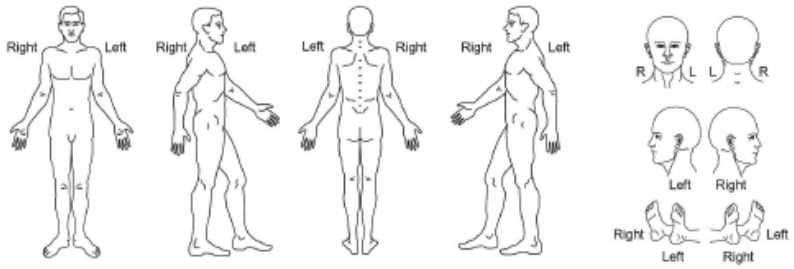
Date: _____

Patient's name: _____ Age: _____ Room: _____

Diagnosis: _____ Physician: _____

Nurse: _____

I. **Location:** Patient or nurse marks drawing



II. **Intensity:** Patient rates the pain. Scale used: _____

Present: _____

Worst pain gets: _____

Best pain gets: _____

Acceptable level of pain: _____

III. **Quality:** (Use patient's own words, e.g., prick, ache, burn, throb, pull, sharp)

_____

IV. **Onset, duration, variations, rhythms:** _____

_____

V. **Manner of expressing pain:** _____

_____

VI. **What relieves the pain?** _____

Brief Pain Inventory

Study ID# _____ Hospital# _____

Do not write above this line

Date: _____ Time: _____

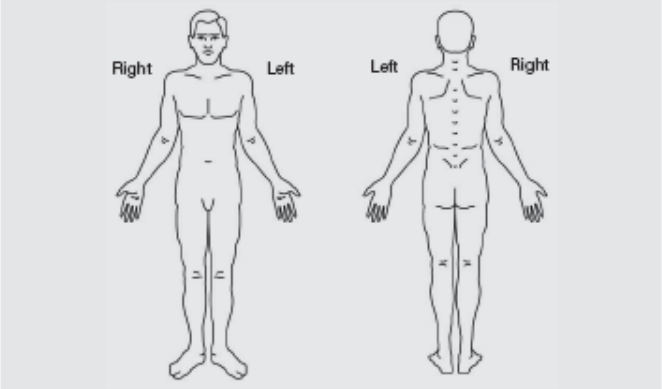
Name: _____

Last First Middle Initial

1) Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

1. Yes 2. No

2) On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3) Please rate your pain by circling the one number that best describes your pain at its WORST in the past 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

4) Please rate your pain by circling the one number that best describes your pain at its LEAST in the past 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

Memorial Pain Assessment Card

4 Mood Scale

Worst mood — Best mood

Put a mark on the line to show your mood.

2 Pain Description Scale

Moderate
Just noticeable
Strong
No pain
Mild
Excruciating
Severe
Weak

Circle the word that describes your pain.

1 Pain Scale

Least possible pain — Worst possible pain

Put a mark on the line to show how much pain there is.

3 Relief Scale

No relief of pain — Complete relief of pain

Put a mark on the line to show how much relief you get.

Fold page along broken line so that each measure is presented to the patient separately in the numbered order.

A7012-AS-9

Condensed Memorial Symptom Assessment Scale [CMSAS]

Condensed Memorial Symptom Assessment Scale (CMSAS)

How much did this symptom bother or distress you in the past 7 days?

Symptom	Present	Not at all	A little Bit	Some what	Quite a bit	Very much
Lack of energy*	Y N	0	1	2	3	4
Lack of appetite*	Y N	0	1	2	3	4
Pain*	Y N	0	1	2	3	4
Dry mouth*	Y N	0	1	2	3	4
Weight Loss*	Y N	0	1	2	3	4
Feeling drowsy*	Y N	0	1	2	3	4
Shortness of breath*	Y N	0	1	2	3	4
Constipation	Y N	0	1	2	3	4
Difficulty sleeping*	Y N	0	1	2	3	4
Difficulty concentrating*	Y N	0	1	2	3	4
Nausea	Y N	0	1	2	3	4

How frequently did these symptoms occur during the last week?

Symptom	Present	Rarely	Occasionally	Frequently	Almost constantly
Worrying	Y N	1	2	3	4
Feeling sad	Y N	1	2	3	4
Feeling nervous	Y N	1	2	3	4

The scoring is similar to that for the MSAS Short Form
For the top box (physical symptoms), weights of zero for N, 0.8 for not at all, 1.6 for a little bit, 2.4 for somewhat, 3.2 for quite a bit, and 4.0 for very much. The average of the starred symptoms would be the PHYS subscale.
For the bottom box (psychological symptoms), weights of zero for N, 1 for rarely, 2 for occasionally, 3 for frequently, 4 for almost constantly. The average of the 3 symptoms would be the PSYCH subscale.

Chang et al, (2004)

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Edmonton Symptom Assessment System (ESAS)

Edmonton Symptom Assessment System:
Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10 Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10 Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10 Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10 Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10 Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10 Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10 Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10 Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10 Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10

Patient's Name _____

Date _____ Time _____

Complete by *(check one)*
☐ Patient
☐ Caregiver
☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

M.D. Anderson Symptom Inventory Core Items

Part I. How severe are your symptoms?

People with cancer frequently have symptoms that are caused by their disease or by their treatment. We ask you to rate how severe the following symptoms have been *in the last 24 hours.* Please fill in the circle below from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be) for each item.

	Not Present 0	1	2	3	4	5	6	7	8	9	As Bad As You Can Imagine 10
1. Your **pain** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
2. Your **fatigue (tiredness)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
3. Your **nausea** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
4. Your **disturbed sleep** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
5. Your **feelings of being distressed (upset)** at its W	○	○	○	○	○	○	○	○	○	○	○
6. Your **shortness of breath** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
7. Your **problem with remembering things** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
8. Your **problem with lack of appetite** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
9. Your **feeling drowsy (sleepy)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
10. Your having a **dry mouth** at its WORST?	○	○	○	○	○	○	○	○	○	○	○

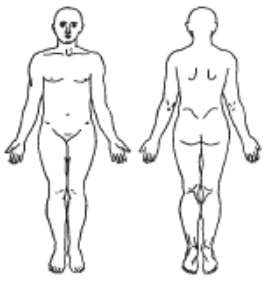
McGill Pain Questionnaire

RONALD MELZACK

Patient's Name _____ Date _____ Time _____ am/pm

PRI: S _____ A _____ E _____ M _____ PRI(T) _____ PPI _____
(1-10) (11-15) (16) (17-20) (1-20)

1 FLICKERING QUIVERING PULSING THROBBING BEATING POUNDING	11 TIRING EXHAUSTING	BRIEF MOMENTARY TRANSIENT
2 JUMPING FLASHING SHOOTING	12 SICKENING SUFFOCATING	RHYTHMIC PERIODIC INTERMITTENT
3 PRICKING BORING DRILLING STABBING LANCINATING	13 FEARFUL FRIGHTFUL TERRIFYING	CONTINUOUS STEADY CONSTANT
4 SHARP CUTTING LACERATING	14 PUNISHING GRUELLING CRUEL VICIOUS KILLING	
5 PINCHING PRESSING GNAWING CRAMPING CRUSHING	15 WRETCHED BLINDING	
6 TUGGING PULLING WRENCHING	16 ANNOYING TROUBLESOME MISERABLE INTENSE UNBEARABLE	
7 HOT BURNING SCALDING SEARING	17 SPREADING RADIATING PENETRATING PIERCING	
8 TINGLING ITCHY SMARTING STINGING	18 TIGHT NUMB DRAWING SQUEEZING TEARING	
9 DULL SORE HURTING ACHING HEAVY	19 COOL COLD FREEZING	
10 TENDER TAUT RASPING SPLITTING	20 NAGGING NAUSEATING AGONIZING DREADFUL TORTURING	
	PPI 0 NO PAIN 1 MILD 2 DISCOMFORTING 3 DISTRESSING 4 HORRIBLE 5 EXCRUCIATING	



E = EXTERNAL
I = INTERNAL

COMMENTS:

Karnofsky Performance Status Scale

DEFINITIONS	RATINGS(%)	CRITERIA
Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.

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COH Quality of Life Scale Cancer Patient / Cancer Survivor

Directions: We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life at this time.

Please circle the number from 0 - 10 that best describe your experiences:

Physical Well Being

To what extent are the following a problem for you:

1. Fatigue

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

2. Appetite changes

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

3. Aches or pain

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

4. Sleep changes

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

5. Constipation

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

6. Nausea

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

7. Menstrual changes or fertility

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

8. Rate your overall physical health

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

COH: Eliminating Barriers to Pain and Fatigue Management

Pain Management

~

www.cityofhope.org/prc/pt-familyed.asp

Available in English & Spanish

Name: _____
MRN#: _____

Passport to Comfort – Pain Management

Current "Location" Rate your current pain intensity. How much pain do you have?

0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10
None at all — Worst ever

Destination Your pain level goal:

0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10
None at all — Worst ever

Your Goals:

Flight Plan The plan for your pain relief:

Date	Medication	Dose	Schedule	Comments

Other Treatments Suggested (i.e. non-drug)

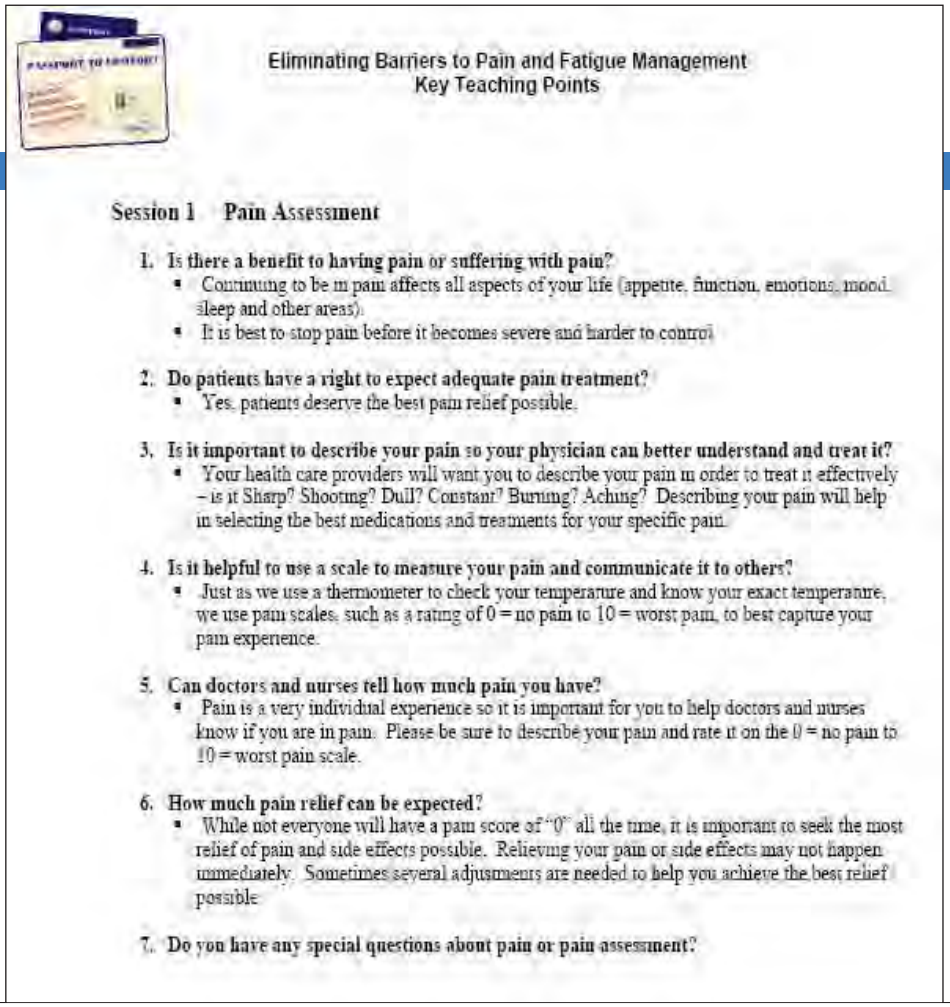
Method	Instructions

Security Check (What to do if your pain or fatigue does not improve):

Call: Evaluation & Treatment Center ext. 85200

Other Notes:

Key Teaching Points: Pain Assessment



Eliminating Barriers to Pain and Fatigue Management
Key Teaching Points

Session 1 Pain Assessment

1. **Is there a benefit to having pain or suffering with pain?**
   - Continuing to be in pain affects all aspects of your life (appetite, function, emotions, mood, sleep and other areas).
   - It is best to stop pain before it becomes severe and harder to control.
2. **Do patients have a right to expect adequate pain treatment?**
   - Yes, patients deserve the best pain relief possible.
3. **Is it important to describe your pain so your physician can better understand and treat it?**
   - Your health care providers will want you to describe your pain in order to treat it effectively – is it Sharp? Shooting? Dull? Constant? Burning? Aching? Describing your pain will help in selecting the best medications and treatments for your specific pain.
4. **Is it helpful to use a scale to measure your pain and communicate it to others?**
   - Just as we use a thermometer to check your temperature and know your exact temperature, we use pain scales, such as a rating of 0 = no pain to 10 = worst pain, to best capture your pain experience.
5. **Can doctors and nurses tell how much pain you have?**
   - Pain is a very individual experience so it is important for you to help doctors and nurses know if you are in pain. Please be sure to describe your pain and rate it on the 0 = no pain to 10 = worst pain scale.
6. **How much pain relief can be expected?**
   - While not everyone will have a pain score of "0" all the time, it is important to seek the most relief of pain and side effects possible. Relieving your pain or side effects may not happen immediately. Sometimes several adjustments are needed to help you achieve the best relief possible.
7. **Do you have any special questions about pain or pain assessment?**

Key Teaching Points: Pain Management

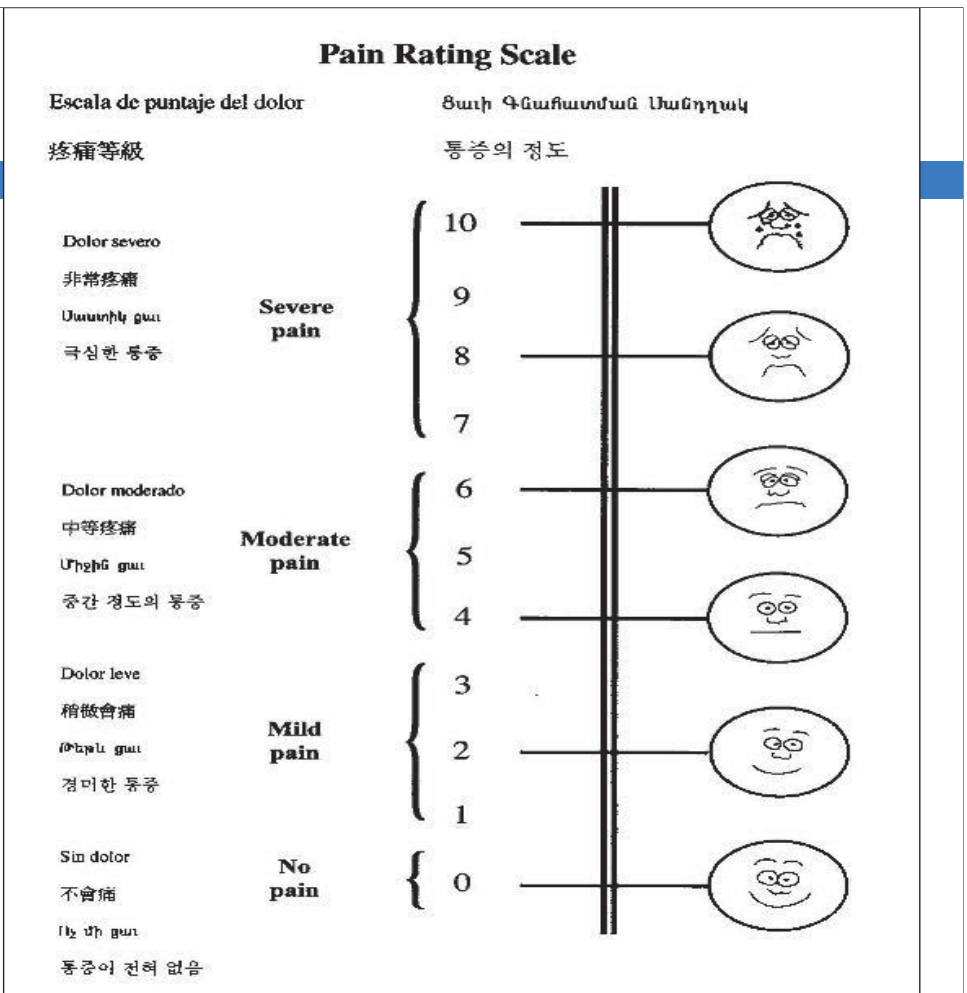
Eliminating Barriers to Pain and Fatigue Management
Key Teaching Points

Session 2 Pain Management

1. **Can pain usually be well controlled with medications taken by mouth?**
   - Yes, the vast majority of patients have pain relieved through taking medicines by mouth.
2. **If these medications do not work, are many other options available?**
   - There are many kinds of medications available and many ways of giving these medications. If oral medications are not effective, there are other routes available.
3. **When morphine and morphine-like medications are used to relieve pain, is addiction a problem?**
   - The same pain medications used in cancer care, such as morphine or oxycodone are rarely, but sometimes abused. Addiction occurs rarely in people who are taking medications for pain.
4. **If you take strong pain medications now, will they still work later?**
   - Yes, pain medications can be taken over months and years and doses can be adjusted as needed.
5. **Do patients often take less medication than is prescribed?**
   - Patients often take less pain medications in order to reduce the side effects.
   - The best approach is to balance the best pain relief with the fewest side effects possible.
   - Patients may also take less medication than is prescribed for other reasons, such as lack of money to pay for them or other issues.
6. **What kinds of medications are used for pain?**
   - Treatment of pain may include a combination of non-opioids (such as Motrin or Tylenol), opioids (such as morphine, oxycodone, hydrocodone) and other medications.
7. **Do pain medications cause side effects?**
   - The most common side effects of pain medication are constipation and sedation.
   - Side effects of medicines for pain must be aggressively treated. Tell your doctor or nurse before side effects become severe.
8. **Are treatments other than medications also helpful for pain?**
   - Many things can help your pain beyond just taking medications. Heat, cold or exercise may help or relaxation, imagery and distraction may be of use.
9. **Do you have any special questions about pain management?**
10. **Please tell your doctor or nurse if you are having any difficulty getting your medications or concerns about taking them. They have dealt with these issues before and will help you.**

COH Modified Pain Rating Scales

In English Spanish Mandarin Armenian and Korean



What kind of pain?

1. aching
2. burning
3. cramping
4. crushing
5. dull
6. sharp
7. shooting
8. squeezing
9. throbbing
10. radiating

¿Qué tipo de dolor es?

1. dolor punzante
2. ardor
3. calambres
4. dolor aplastante
5. dolor sordo
6. dolor agudo
7. pinchazos
8. dolor con opresión
9. dolor palpitante
10. dolor con irradiación (dolor que corre de un lado a otro)

疼痛的類型

1. 疼痛
2. 燒灼感
3. 抽搐痛
4. 壓迫性疼痛
5. 悶痛
6. 劇痛
7. 陣陣刺痛
8. 絞痛
9. 跳痛
10. 擴散痛

Ի՞նչ տեսակի ցաւ՝

1. մոկսացնող
2. այրող
3. ջղաձգող
4. ճնշող
5. բութ
6. սուր
7. ծակող
8. ճմլող
9. բաբախող
10. տարածուող

어떠한 통증을 느끼십니까?

1. 쑤시는 통증
2. 화끈화끈한 통증
3. 결림
4. 갑갑함
5. 둔한 통증
6. 날카로운 통증
7. 쏘는 듯한 통증
8. 조이는 통증
9. 욱신욱신한 통증
10. 퍼져나가는 통증

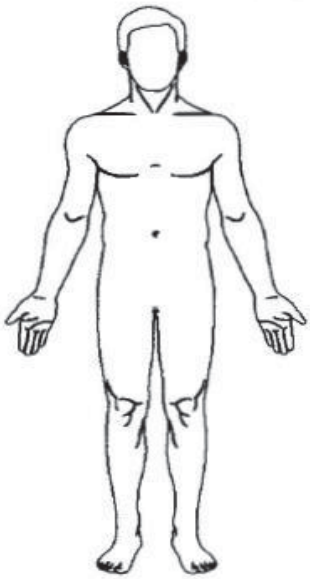
Please show me where the pain is (location in your body).

Por favor muéstreme dónde está el dolor (ubicación en el cuerpo).

請告訴我疼痛的位置 (您身體的什麼部位)。

Խնդրեմ ցոյց տուէք որտե՞ղ է ցաւը (մարմնի ո՞ր մասում):

몸의 어느 부분에 통증이 느껴지는 지 나타내십시오.



Psychosocial Pain Assessment Form

PSYCHOSOCIAL PAIN ASSESSMENT FORM

INSTRUCTIONS FOR USE

This tool was designed to standardize a comprehensive psychosocial pain assessment for an interdisciplinary pain service. Through the use of a guided interview process, the clinician explores the impact of unrelieved pain on the patient/family experience in the following domains: Economic, Social Support, Activities of Daily Living, Emotional Impact, and Coping Style.

Page 2 is designed to provide a synopsis of the patient/family situation. It is designed to be completed following the guided interview as a summary for clinical reference and to aid in a brief presentation for an interdisciplinary pain meeting. It includes the interviewer's impressions, interventions and recommendations as well as a summary of the key domains and associated level of concern.

Pages 3-8 contain questions regarding the five domains listed above. Following the questions in each domain is the opportunity for the patient and family (significant other) to rate their individual level of concern via a 0-10 rating scale (0 = no concern; 10 = greatest concern). Based upon their interpretation of the interview, the interviewer rates their subjective impressions of the patient's level of concern. If a family member or significant other is present, their rating is then asked and finally the patients rating. Coherence and discrepancies in ratings amongst the interviewer, patient and family are noted and may be explored for clinical significance.

Additionally, the assessment of prior history (including traumas such as physical and sexual abuse or unresolved losses) helps a clinician to focus interventions that respect past difficulties as well as past strengths and coping skills that may be transferable to the current pain experience.

This assessment tool is available in English and in two Spanish versions (children/adolescents and adults). Contact Shirley Otis-Green, LCSW (sotis-green@coh.org) with any questions regarding usage.

City of Hope

PSYCHOSOCIAL PAIN ASSESSMENT FORM

Introduction

We recognize that people are often concerned about the impact of pain on many areas of their lives. Unrelieved pain can cause economic, emotional, spiritual and social problems in addition to medical and physical ones. We will be looking at the overall impact of pain in your life and asking several questions to help the Pain Team better understand your personal concerns. The first area we will be addressing is the economic impact of your pain.

Economic

1. How are you supporting yourself financially?
   Work _____ Family _____ Disability _____
   Partner _____ Retirement/Pensions _____ Other _____
   Friends _____ Savings _____
2. Some people we see are concerned about meeting their economic needs.
   Which of these are worrisome to you?
   None _____
   Housing _____ Clothing _____ Prescriptions _____
   Food _____ Childcare _____ Insurance _____
   Transportation _____ Medical bills _____ Other _____
3. How has your economic situation changed? **Better** _____ **Worse** _____
   Describe: _____
4. How upsetting have these changes been to you?
   Describe: _____
5. What would be different in your life if you could afford to change it?
   Describe: _____
6. Please rate your overall level of concern regarding these economic issues.
   Rating (0-10) (0 = no concern, 10 = greatest concern)

	Interviewer	Patient	Significant Other
Economic			

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PSYCHOSOCIAL PAIN ASSESSMENT FORM

Social Support

We believe that pain affects not just you, but your entire family. We'd like to look at ways in which you've noticed this impact.

1. Who do you turn to when you're uncomfortable or in pain?
   Self_____ **Others** _____**God**_____
   Name: _____ Relationship: _____
   How accessible is this person to you? _____
   How helpful is this to you? _____
2. How comfortable are you sharing your feelings/fears with your loved ones?
   What makes this difficult for you?
   Describe:
   _____
   _____
   _____
3. How satisfied are you with communication with your doctor/medical team?
   Describe:
   _____
   _____
   _____
4. Losing people who are important to us affects us deeply. Have you suffered any recent losses?
   Yes___ **No** ___
   Describe:
   _____
   _____
   _____
   Breaking up_____ Separation _____ Divorce_____
   Death _____ Moving away _____ Other _____
5. Please rate your overall level of concern regarding these social support issues.
   Rating (0-10) (0 = no concern, 10 = greatest concern)

	Interviewer	**Patient**	**Significant Other**
Social support			

PSYCHOSOCIAL PAIN ASSESSMENT FORM

Activities of Daily Living

Physical Impact

Often unrelieved pain affects a person's daily routine. How has your pain impacted you in these activities of daily living?

1. Affecting your sleeping patterns? **Yes** ____ **No** ____
   Frequent napping _____ Difficulty going to sleep _____
   Nightmares _____ Difficulty staying asleep _____
   Drowsiness _____ Difficulty waking up _____
   Chronic Fatigue _____ Other _____
2. Affecting your eating habits? **Yes**_____ **No**_____
   Weight loss/gain _____ Special Diet _____
   Loss of appetite _____ Feeding Tube _____
   Nausea/vomiting _____ Difficulty swallowing _____
   Changes in taste _____ Other _____
3. Affecting your hygiene/elimination habits? **Yes** _____ **No**_____
   Diarrhea _____ Constipation _____
   Catheter _____ Ostomy _____
   Difficulty Grooming _____ Incontinence _____
   Difficulty Bathing _____ Other _____
4. Affecting your ability to move? **Yes**_____ **No**_____
   Generalized weakness _____ Limited range of motion _____
   Bed bound _____ Wheel chair _____
   Crutches/walker/cane _____ Walking/standing _____
   Getting in/out of car _____ Climbing stairs _____
   Lifting/carrying _____ Other _____
   No longer athletic _____ S.O.B. _____
5. Affecting your roles in your family? **Yes**_____ **No**_____
   In what ways?
   _____
6. Affecting your sexual functioning? **Yes**_____ **No**_____
   In what ways?
   _____
7. Affecting your physical appearance? **Yes**_____**No**_____
   In what ways?
   _____
8. How has your energy level changed? Less_____ Same_____ Improved _____
9. Please rate your overall level of concern regarding these physical changes.
   Rating (0-10) (0 = no concern, 10 = greatest concern)

	Interviewer	**Patient**	**Significant Other**
Activities of daily living	_____	_____	_____

PSYCHOSOCIAL PAIN ASSESSMENT FORM

Emotional

Pain affects our emotions. These questions will help us better understand your pain's impact upon you emotionally.

1. Have you been troubled by feelings of:
   Depression **Yes** ___ **No**___ *Describe:* _____
   Frustration/Anger **Yes** ___ **No** ___ *Describe:* _____
   Anxiety **Yes**___ **No**___ *Describe:*_____
   Panic Attacks **Yes**___ **No**___ *Describe:* _____
   Mood Swings **Yes**___ **No**___ *Describe:* _____
   Difficulty Concentrating **Yes**___ **No**___ *Describe:* _____
   Loss of Motivation **Yes** ___ **No**___ *Describe:* _____
2. Do you ever see or hear things that others don't? **Yes** ___ **No**___
   Describe:
   _____
   _____
3. Are there any medical tests or procedures that frighten you? **Yes** ___ **No**___
   Describe:
   _____
   _____
4. Have you ever thought about hurting yourself or taking your life? **Yes**___ **No**___
   Describe:
   _____
   _____
5. Please rate your overall level of concern regarding these emotional issues.
   Rating (0-10) (0 = no concern, 10 = greatest concern)

	Interviewer	**Patient**	**Significant Other**
Emotional issues			

PSYCHOSOCIAL PAIN ASSESSMENT FORM

Coping

People handle pain and distress in many ways. These questions will help us to better understand how you cope with upsetting situations.

1. Sometimes, doing things we enjoy distracts us from our pain. What activities are you able to do that you enjoy?
   None _____

Family _____	Friends _____	Hobbies _____	Reading _____
Religion _____	Gardening _____	Traveling _____	Exercise _____
Art/Music _____	TV _____	Pets _____	Other: _____

2. Some people find comfort in spirituality to help them cope with difficult situations. What role does spirituality have in helping you?
   Describe:
   _____
   _____
3. Many people in your situation ask "Why did this happen to me?" How have you attempted to "make sense" of your painful experiences?
   Describe:
   _____
   _____
4. Past stressful events can impact us in the present. What kinds of stress have you had to handle before? *Describe:*
   _____
   _____
   Child abuse? **Yes**___ **No**___ *Describe:* _____
   Sexual abuse? **Yes**___ **No**___ *Describe:* _____
   Family violence? **Yes**___ **No**___ *Describe:* _____
5. Some people find that counseling sessions or attending support groups can help them cope with stressful situations.
   Have you ever been in counseling? **Yes** ___**No**___ What was the focus of your therapy?_____
   Have you ever attended a support group? **Yes** ___**No**___ What kind? _____
   How helpful was this?
   _____
6. Some people are prescribed medications to help them cope. Which of these have you been prescribed?
   None _____
   Other: _____
   Anti-Anxiety medications? **Yes**___ **No** ___ *Describe:* _____
   Anti-Depressant medications? **Yes**___ **No** ___ *Describe:* _____
   Pain Medications? **Yes**___ **No**___ Describe: _____
   Do you ever take your prescriptions differently than ordered? **Yes** ___**No**___
   Describe: _____

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PSYCHOSOCIAL PAIN ASSESSMENT FORM

Coping continued

7. Some people use other chemicals to help them cope. Which of these do you use?

   Tobacco? **Yes** ____ **No** ____ *Describe:*_____

   Alcohol? **Yes** ____ **No** ____ *Describe:*_____

   Recreational Drugs? **Yes** ____ **No** ____ *Describe:*_____

   Have you ever tried to stop using these? **Yes** ____ **No** ____ *Describe:*_____

   Do you worry about your usage of these? **Yes** ____ **No** ____ *Describe:*_____

   Has your family worried about your usage of these? **Yes** ____ **No** ____ *Describe:*_____

8. What changes do you expect in your future?

   Describe: _____

9. Overall, how satisfied are you with your present quality of life?

   Describe: _____

10. Please rate your overall level of concern regarding your ability to cope or manage your pain.

Rating (0-10)	(0= no concern, 10 = greatest concern)		
	Interviewer	**Patient**	**Significant Other**
Coping	_____	_____	_____

Developed by: Shirley-Otis-Green, MSW, LCSW
City of Hope National Medical Center

Publications

Otis-Green, S. (2006). Psychosocial Pain Assessment Form. In Dow (Ed.), Nursing Care of Women with Cancer. St. Louis, MO: Elsevier Mosby, 556-561.

Otis-Green, S. (2005). Psychosocial Pain Assessment Form. In Kuebler, Davis, Moore (Eds.), Palliative Practices: An Interdisciplinary Approach. St. Louis, MO: Elsevier Mosby, 462-467.

The Psychosocial Pain Assessment Form can be found on the City of Hope Pain/Palliative Resource Center website at

http://www.cityofhope.org/prc/pain_assessment.asp (English)

http://www.cityofhope.org/prc/pdf/Forma%20%20Adultos%20PS.pdf (Spanish - Adults)

http://www.cityofhope.org/prc/pdf/Formulario%20Ninos.pdf (Spanish - Children/Adolescents)

Key Features

- Awareness of discrepancies in ratings invites discussion regarding how perceptions can be misinterpreted
- Encourages prioritization of interventions
- Offers information regarding spiritual/existential concerns and coping strategies
- Provides “snapshot” for team discussion

Key Takeaway:
Assess,
Don't Assume!

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Pain & Symptoms as Stress

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Stress

- Environmental conditions that require behavioral adjustment

Benson, (1975)

- A perception of threat to one's physical & or emotional well being; a perception that one's resources are insufficient to meet the threat

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Identification of Stressors

- Thoughts / beliefs / fears
- Persons
- Events
- Physical sensations
- Places or situations
- Demands

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Relaxation Response

- Feeling of relaxation / well being
- Mastery & control
- Decreased heart rate, blood pressure, respiratory rate, blood flow to periphery, metabolic rate (sweating, trembling, weakness)

Benson, (1975)

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Assessment Questions

Loscalzo & Jacobsen, (1990)

- Where is the pain?
- What does the pain feel like right now?
- What does the pain feel like at its worst?
- What do you think is the cause of your pain? What has your doctor told you about the cause of your pain?
- Can you describe the pain so I can understand how you experience it?
    - size, weight, color, temperature, texture

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Assessment Questions

- What makes the pain worse or better?
- What do you do to make the pain hurt less?
- What has been your past experience with pain?
- Do you feel you can be helped to deal more effectively with the pain?
- What do you think would help you?
- What was your life like before the pain?

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Assessment Questions

- What do your family& staff think & feel about your pain?
- How do your family & staff react when you demonstrate pain behaviors?
- How do your family respond to the restrictions you have made in your life because of the pain?
- How do cultural & spiritual beliefs impact your &/or your family's view of the pain?

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Assessment Questions

- If you did not have pain, what might you be doing differently?
- What is your worst fear or fantasy concerning your pain?
- What would happen if your worst fear or fantasy were realized?

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Assessment Questions

- Where do you feel safest & most comfortable?
- Can you create a pleasant experience in your imagination in which you can get emotionally involved?
- Can you vividly imagine that experience right now?

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Modifiers of Pain Perception

- Functional limitations & disability
- Insomnia & fatigue
- Communication challenges
- Depression, anxiety, demoralization & anger
- Social, familial & financial problems
- Cultural or spiritual beliefs
- Despair, lack of meaning
- Symptomatic preoccupation

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Possible Interventions

- Family meeting
- Education
- Spiritual counseling
- Life review
- Environmental
- Advocacy
- Cognitive behavioral interventions
- Supportive counseling

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Interventions

- Pharmacologic
- Complementary
  - Prayer
  - Heat, cold
  - Interventional
  - Physiatric
  - Music, massage
  - Therapeutic touch

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Strategies to Minimize Suffering

- Encourage life review
- Reframing of experiences
- Draw wisdom from culturally-relative theological/philosophical/mythical stories
- Normalization of experiences (group sharing & support)
- Cognitive-behavioral interventions for symptom management / decision making

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Supportive Counseling

- Ventilation
- Exploration
- Clarification
- Validation
- Partializing

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Cognitive Behavioral Interventions

- Interventions based in the acceptance & acknowledgement that an individual & family's experience is influenced by interrelated & modifiable factors including:
  - Physical
  - Cognitive
  - Emotional
  - Behavioral

Jacobsen & Hann, (1998)

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Cognitive Behavioral Interventions - Goals

- Maximize feelings of control, coping & engagement with life
- Modify global experience of hopelessness, helplessness & suffering
- Adjuncts to medical management of illness & symptoms (pain, insomnia, fatigue etc)
- Minimize or correct distorted perceptions & their impact
- Decrease physiologic tension, stress, symptom cycle
- Promote acceptance of medical/ pharmacologic treatments

Psychosocial Interventions

- Anticipate possibilities
  - Consider back up plans
  - Response shift – as experience evolves
  - Decisions change
- Uncertainty
  - Validate & explore
- Educate
- Individualize & normalize

Pain

CANCER RELATED PAIN

♦ Cancer pain is a common problem that can cause needless suffering.

♦ Pain may result from the cancer itself, treatment for the cancer or a combination of factors.

HOW CAN I TALK ABOUT MY PAIN?

♦ Only the person experiencing the pain can accurately describe the pain and rate its intensity.

♦ By rating your pain on a scale of 0-10 (0 =no pain, 10 = worst pain possible), adjustments can be made to medications to achieve the best pain relief.

♦ By describing how the pain feels, you will be able to give the doctor or nurse a better idea of what may be causing the pain and what medications should be used to treat it.

QUESTIONS ABOUT MANAGING PAIN

SHOULD I WAIT UNTIL THE PAIN BECOMES BAD BEFORE TAKING THE PAIN MEDICATION?

♦ Waiting until the pain becomes severe makes the pain more difficult to control.

♦ If you wait, you may need more pain medication which can lead to more side effects.

♦ When you take pain medication on a regular basis, you actually use less medication.

WHY DO I FEEL SO MOODY?

♦ When you have pain, it is not unusual to feel sad, lonely, anxious or depressed. These feelings can make your pain worse, and also may require treatment.

♦ If you are feeling any of these symptoms, please talk to your physician, nurse, psychologist, social worker or pastoral care advisor.

WILL I BECOME ADDICTED TO PAIN MEDICATION?

♦ Addiction is one of the most common fears among patients, caregivers and even some doctors and nurses. Studies show that less than 1% of patients taking opioids for long periods of time became "addicted".

♦ Addiction describes a psychological need to take medication for reasons other than treating pain. Patients seldom experience a "high" with pain medications. Instead there is a return to feeling "normal" once the pain is relieved.

If pain continues to be a problem

TALK TO YOUR DOCTOR

about a referral to the Supportive Care & Palliative Medicine Pain Team

WHY DO I HAVE MORE THAN ONE MEDICATION ORDERED FOR MY PAIN?

♦ There are different types of pain and each pain may respond to a different type of medication. A "long acting" opioid may be ordered for persistent pain, while a "short acting" opioid can be taken as needed every 3-4 hours for intermittent breakthrough pain.

♦ Other medications may help specific types of pain (e.g.: anti-seizure drugs and certain antidepressants for pain from nerve involvement).

WHAT SIDE EFFECTS CAN PAIN MEDICATIONS CAUSE?

♦ There are some side effects that occur when an opioid is first started, and these are generally time-limited.

♦ The three most common side effects are: nausea, constipation and sleepiness.

♦ These side effects can be minimized or prevented from occurring. Please report any side effects you may have to your doctor or nurse.

OTHER NON-DRUG MEASURES FOR PAIN RELIEF

Biofeedback
Imagery
Self-hypnosis
Relaxation techniques
Exercise/mild toning/stretching
Use of heat/cold
Yoga
Counter-irritants:
Capsaicin
Icy Hot/Ben Gay
Tiger Balm

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Behavioral Interventions

- Self-monitoring (Diaries & Journals)
- Graded task assignment
- Differential reinforcement
- Systematic desensitization
- Assertiveness training
- Shaping & modeling
- Behavioral rehearsal
- Relaxation

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Cognitive Interventions

- Information & education
- Cognitive restructuring
- Thought stopping
- Coping statements
- Imagery
- Cognitive distractions

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Cognitive Interventions

Coping statements - statements which distract, enhance coping &/or diminish the threatening aspect of a situation or experience. Catastrophic & defeating self-statements are replaced with internal dialogues that enhance coping & competence.

McCaul & Malott, 1984

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Cognitive Distortions

- All or nothing thinking
  - Always; never
- Overgeneralization
  - Because I have pain now I will die in agony
- Catastrophizing
  - The pain in my back means I will be paralyzed

More Effective Coping Statements

- "I have had this pain before; it comes & goes"
- "I can influence some aspects of my pain"
- "There are many ways I can continue to contribute to the lives of family & friends"
- "God is always with me"
- "I can be both dependent on others & guiding my care"

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Cognitive Behavioral Interventions

Imagery - the use of mental representations to help control symptoms, enhance relaxation, mentally rehearse activities & feelings, comfort, create distance, or give insight. Visualization is the most common form but exercises can be enriched by involving the other senses.

Sheikh, (1983); Graffam & Johnson, (1987)

Cognitive Behavioral Interventions

Distraction - refocusing attention to stimuli other than pain & to other aspects of the self –

- Mental activity; internal such as prayer, reading, kaleidoscope, imagine a pleasant place
- Physical activity; external such as breathing, rhythm, engaging in conversation, massage

Syrjala, (1993);Turk, Meichenbaum & Genest (1983)

Segments of a Pain Diary

3/25 - 6:50 PM; Waited an hour but the pain is still there & feels even worse, although I don't think it's really worse. It's just that it won't go away & its driving me crazy (*partializing physical pain from the anxiety & distress caused by ongoing experience of pain & catastrophic thinking).* I'm getting more & more upset & anxious as time passes. I'm thinking - "Is the pain from cancer? When will it go away?" *(internal dialogue reinforces helplessness rather than self efficacy & control)*

Segments of a Pain Diary

3/29 - 2:00 PM; Feeling very depressed – I was supposed to go out to dinner in the city but I cancelled because I feel so horrible. I'm also afraid that I'll be miserable in pain…that's why I cancelled. Now I'm feeling depressed because I feel like this pain has control over my entire life. *(catastrophic thinking & anticipation of pain controls behavior, exacerbating helplessness & distress)*

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Segments of a Pain Diary

6/2 -10:00 PM; Friends came over. We watched a video. I was sitting up on the sofa. I feel good that I'm still doing things socially even when my pain increases a bit. (*modalities of pharmacologic, integrative, supportive & cognitive behavioral interventions combine to assist patient toward age appropriate activities that improve quality of life, return semblance of control in the setting of metastatic breast cancer)*

Procedure Related Pain

- Predictable pain
  - Creates anticipatory fear & anxiety
  - Patients feel victimized & violated by those who are "helpers"
  - Additional physical insult to already stressed & compromised patients

Goals of Procedural Pain Management

- Adequate pain relief during procedure
- Enhance ability to cooperate
- Minimize anxiety & fear
- Encourage prompt safe recovery

Procedural Pain Assessment

- Discuss process for assessing pain with patient during procedure
- Do baseline assessment
- If communication is a problem discuss alternate method for indicating pain
- Observe physical signs, the absence of which does not mean there is no pain

Integrative Interventions

- Not a substitute for analgesics
- May reduce anxiety & promote relaxation
- What have you found effective?
- If techniques require patient participation assess
  - Attention span, energy, concentration
- When facing repetitive procedures, encourage learning of relaxation & imagery
- Practice before procedures

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Engaging Families

- Historians & story tellers
- Collaborators
- Teachers & learners
  - How to comfort
  - Provide written & experiential education
  - Posting in room
  - Share discoveries

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Definitions

- Cognitive Impairment
  - Change in usual pre-morbid state of mind
  - Includes Delirium, Dementia, altered emotions & behaviors.
- Dementia
  - Chronic syndrome characterized by decline in cognitive functions occurring in clear sensorium

Folstein & Folstein, (1994)

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Definitions

- Delirium- Disorder of arousal & cognition
  - Disturbance of consciousness (arousal)
    - Reduced clarity of awareness
    - Decreased ability to focus, sustain & shift attention
  - Change in cognition (not pre-existing)
    - Memory deficit
    - Disorientation, perceptual disturbances
    - Language disturbances (lack of fluency, pauses)

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When Patients Cannot Tell You About Their Pain

- Assess with others - changes in behavior
  - Quiet when normally talkative
  - Restless / sudden anger
  - Loss of appetite
- Watch for pain behaviors like:
  - Agitation / crying out
  - Rubbing
  - Confusion
  - Excessive sleep

Non Communicative /CI

- Etiology - Contributing Factors
  - Fever
  - Change in disease
  - Infection, sepsis
  - Hypoxia
  - Treatment side effects
  - Dehydration
  - Metabolic abnormalities

Non Communicative / CI

- Etiologies
  - Environmental
    - Sensory deprivation - overload
    - Change in setting
      - Hospitalized elderly at increased risk
  - Emotional, Psychosocial, Spiritual
    - Depression
    - Anxiety

Non Communicative

- Have high index of suspicion for pain
- Treat pre-emptively - ***would a person with capacity have pain ?***
- Assessment triggers
  - Deviations from baseline behaviors
    - Changed gait, stillness
    - Changed vocalization
    - Facial grimacing, frowns

Adaptation of Pain Assessment

- Allow time for patient to think & respond
- Shorten sessions to adapt to limited attention span
- Assess frequently - focus on present to adapt for impaired memory
- Enlist observations & support of family / staff familiar with patient (Journal)

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Adaptation of Pain Assessment

- Choose easiest assessment tool
- Provide consistency of staff & tool
- Chart visibly / have tool at bedside
- Use large print, light, hearing / visual aids
- Adapt language to patient

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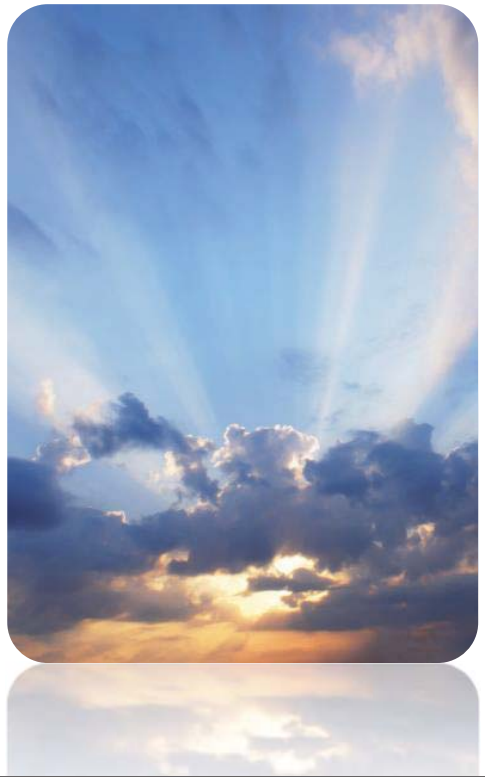
Recommendations For Enhanced Coping



- Share your hopes, dreams, and fears
- Surround yourself with family, friends, pets.
- Enjoy the music and magic of each day.
- Reconnect with traditions that are most meaningful to you.
- Celebrate the miracles that are still to be found each day.

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Encourage

- **"Hope Builders"**: Tap into the arts, faith, music, journaling, poetry, exercise, reading, movies, humor, dance, prayer, ritual, scrap-booking, letter-writing, etc.
- Consider "energy conservation" strategies (partialize tasks) and "sleep hygiene" concepts to maximize energy and minimize fatigue.

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Caregiver Considerations

- **Consider their needs.**
  - Anticipate future challenges so they can be Proactive vs. Reactive.
  - Establish “back-up plans.”
- **Encourage them to self-nurture.**
  - Play/pray with passion.
- **Consider their priorities.**
  - Seek balance.

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Recommendations For Healthier Coping

- Recognize that you have made the best decisions you could at the time with the limited information that you had available.
- Remind yourself to learn from “mistakes” and to be grateful for the opportunity to move forward now with greater wisdom and insight.

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Coping Strategies For Caregivers

- Increase your tolerance of ambiguity (offer guidance and support).
- Mobilize your network of support.
- Identify areas of suffering and create opportunities to address "unfinished business."
- Refer to team for additional support

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Goal: Minimize Regrets!

To the degree that we feel that we have used our unique talents and opportunities wisely, we minimize regrets.

- Seize the moment: acts of *omission* more often a source of regret than acts of *commission*.
- Follow your bliss.
- Live your passion.
- Live as if it matters!
- Make meaning.
- Create moments that matter!

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Take Care of Business…

Ancient Wisdom: "Hope for the best, but prepare for the worst…"

- Durable Power of Attorney for Healthcare
- Estate Planning / Wills
- Guardianship: Establish back-up plans for who will care for those you are responsible for (Children, Parents, Pets, Property, Possessions)
- Identify a surrogate/agent/advocate for decision-making purposes should you not be able to communicate
- Clarify values and goals of care
  - Ensure decisions are reflective of your preferences

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Tasks for Healing Relationships

- ***"I forgive you."***
- ***"Please forgive me."***
- ***"Thank you."***
- ***"I love you."***

~ The Four Things that Matter Most: A Book About Living (2004). Ira Byock, Free Press.

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Concrete Interventions for Caregivers:

- Assist in re-prioritization.
- Reframe experiences in meaningful way.
- Support life review.
- Address "unfinished business" issues.
- Logistics ("What do others need to know/do if you're not here?").
- Resolve responsibilities (dependents, pets).
- Be an on-going advocate for symptom relief.

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"Sitting with Suffering"

- Suffering invites development of "bigger picture" perspective.
- Meet others during a window of vulnerability.
- Shared fragility.
- Celebration of our shared "human-ness."
- Authentically meaningful.
- Recognize "sacred" moments.
- Invitation to live your life as if it matters.

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Caregiving Opportunities

- Immensely rewarding: What you do, *does* matter & is *treasured* by those we serve.
- Recognize the privilege of sharing in this most profound and personal of journeys…
- Joyful caregiving has *transformative* potential for all involved.

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Consider:

Nurses Ask: Is this the right person, the right medicine, the right dose, and is this the right time?

Similarly…

- Are you the right person, doing the right task at the right time?
- If not, explore what other options might exist?
- Dare to delegate!

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Caregiver Coping Strategies

- Adjust expectations.
- Periodically reframe & reprioritize.
- Debrief & de*grief.*
- Accept that "it takes as long as it takes."
- Develop stress relief skills.
- Celebrate even small achievements
- Remember physical self care (exercise, eat, sleep).
- Address your social needs.
- Cultivate relaxation skills.

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Caregiver Coping Strategies

- Nurture yourself (treat yourself as if you were your own best friend).
- Use humor (daily).
- Consider journaling, poetry, art, music, dance, storytelling.
- PLAY daily.
- Recognize your own "center."
- Learn new skills.
- Distinguish when "good enough" *is.*
- Identify, and then ***address*** your own "unfinished business."

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Caregiver Coping Strategies

- Cultivate optimism
  - Practice "making lemonade" from life's lemons.
- Use positive self-talk: Reframe experiences when possible.
- Seek information/education to increase your competence in caregiving

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The Lessons of the Labyrinth

- Cultivate faith in the *process*.
- Seek peace & inspiration amidst apparent setbacks.

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Excellence In Self-Care

- Seek mentors in this work…
- Boundaries and balance are important.
- Practice what you preach: apply the principles you would recommend to others.
- Cultivate the skills you need so that you can do the best job possible.
- Don't underestimate the value of "companioning" and "presence".

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Bottom Line:

- Increase your tolerance of ambiguity.
- Claim responsibility for ***you***.
  - Have the courage of your convictions.
  - Take risks.
  - Live passionately!
- Be "mindful of the moment."
  - Live in the ***now***.

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Suffering...

- Pain + Fear = Suffering
- Patient and family each experience suffering uniquely their own.
- Suffering is always subjective.
- Buddhist Tradition: Suffering is related to our attachments/unmet expectations: "*Pain is experienced in the present, while suffering is future-oriented.*"

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Explore Supportive Resources

- Hospital Support Groups
- Community Support Programs (Gilda's Club, Wellness Community, etc)
- Oncology Social Worker
- Pain Nurse
- Hospital Sponsored Community Educational Programs
- Specialty Pain Services
- Palliative Care Programs

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Team Learning & Collaboration

- Data sharing
  - Not right or wrong – all data to be assessed & understood
  - Ethical codes are not the same
  - Roles & responsibility shared but
  - Consequences & liability differ
- Learn together
  - Journal clubs
  - Joint presentations

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Professionalism and Advocacy: Excellence in Action

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Lessons Learned from Working with Those Facing End of Life

Importance of:

- Living Authentically
- Minimizing Regrets
- Identification and Prioritization of What ***Really*** Matters
- Making a Difference
- Appreciation of Opportunities

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Reflection Question…

If one of your loved ones were to be cared for in your institution or community would you be satisfied with the experience they are likely to have?

If not, let this guide your next steps…

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Excellence isn't Optional It's our Commitment!

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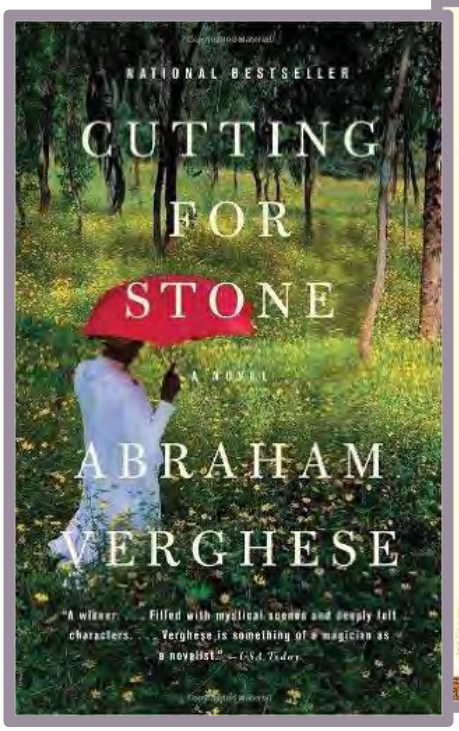
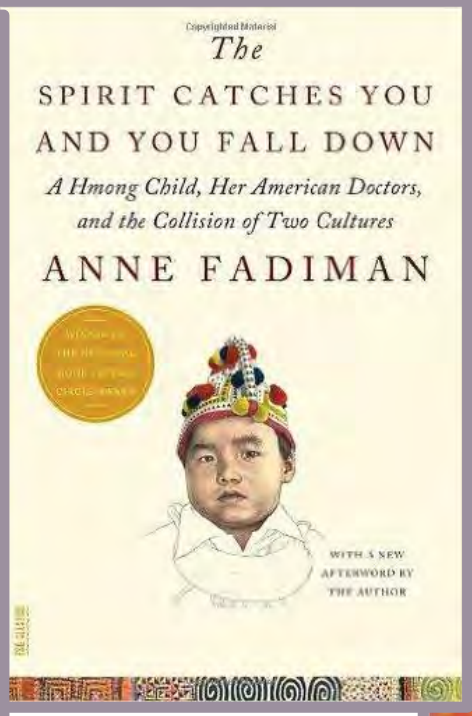
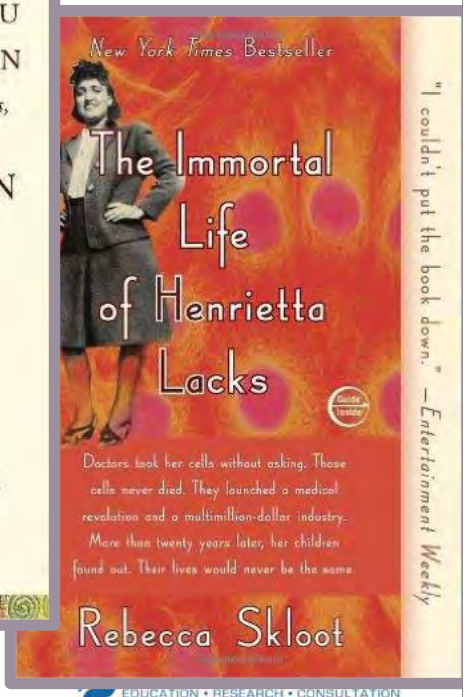
Recommended Reading







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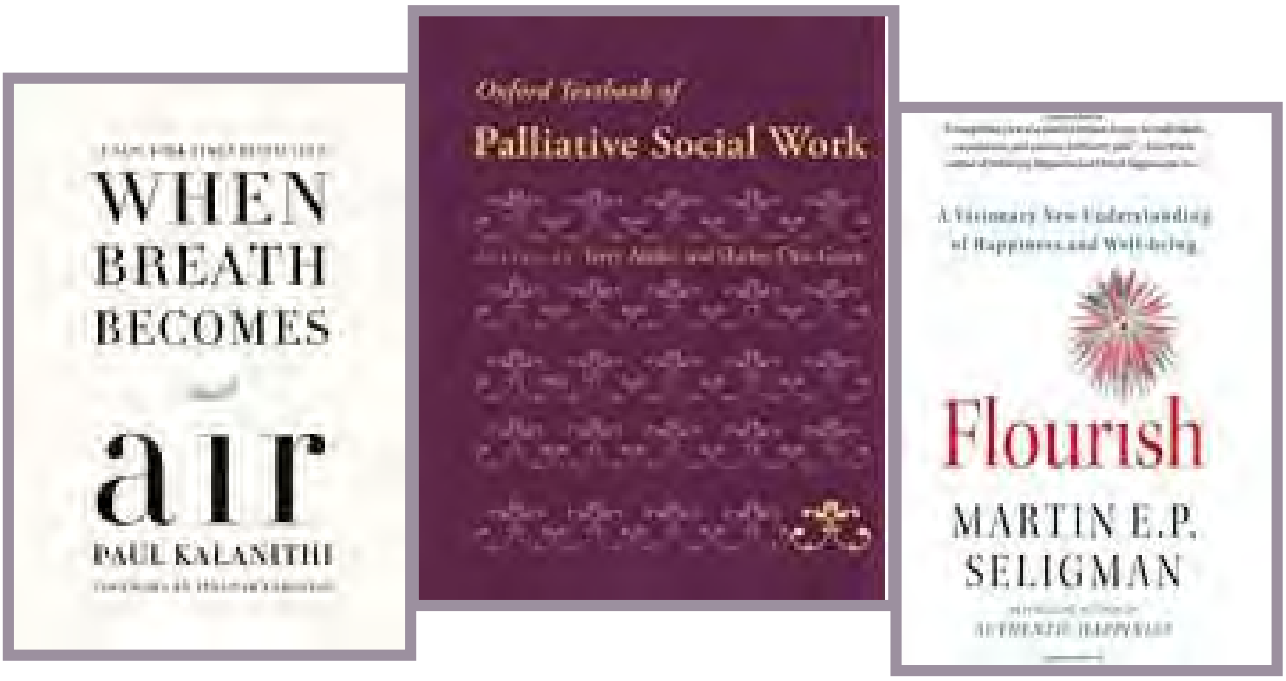
Additional Reading



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Resources

- Coalition for Compassionate Care of California
  - http://coalitionccc.org/
- Prepare For Your Care
  - https://www.prepareforyourcare.org/
- Caring Connections
  - http://www.caringinfo.org/
- The Conversation Project
  - http://theconversationproject.org/

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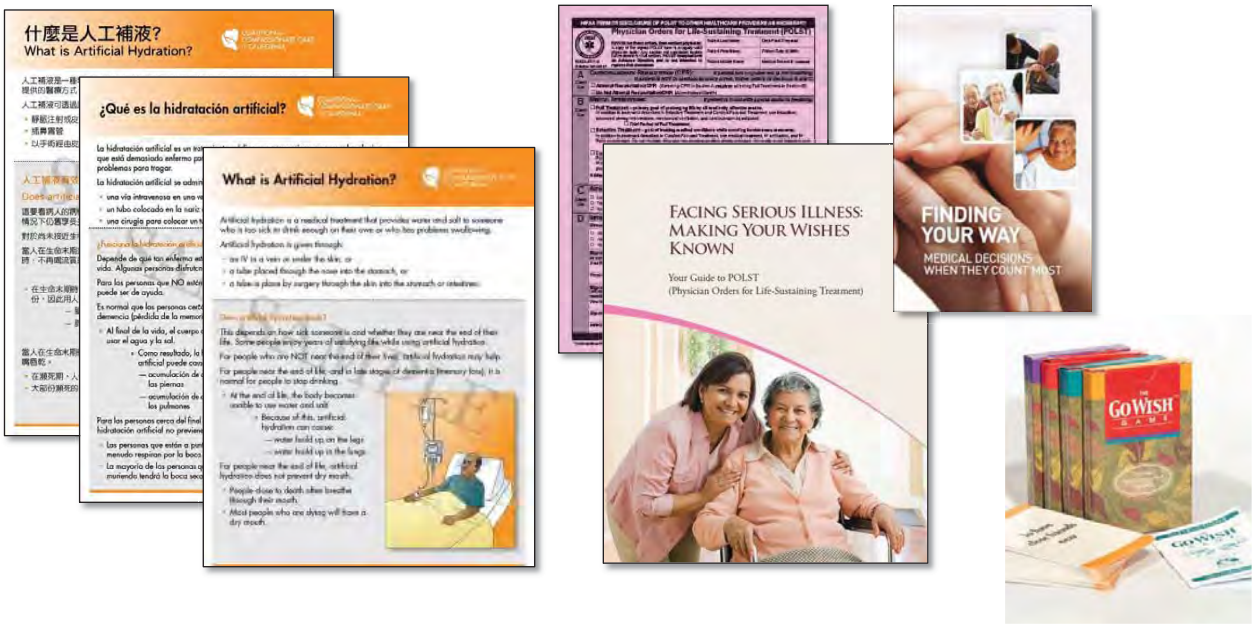
Materials to support patients and providers



CoalitionCCC.org/store

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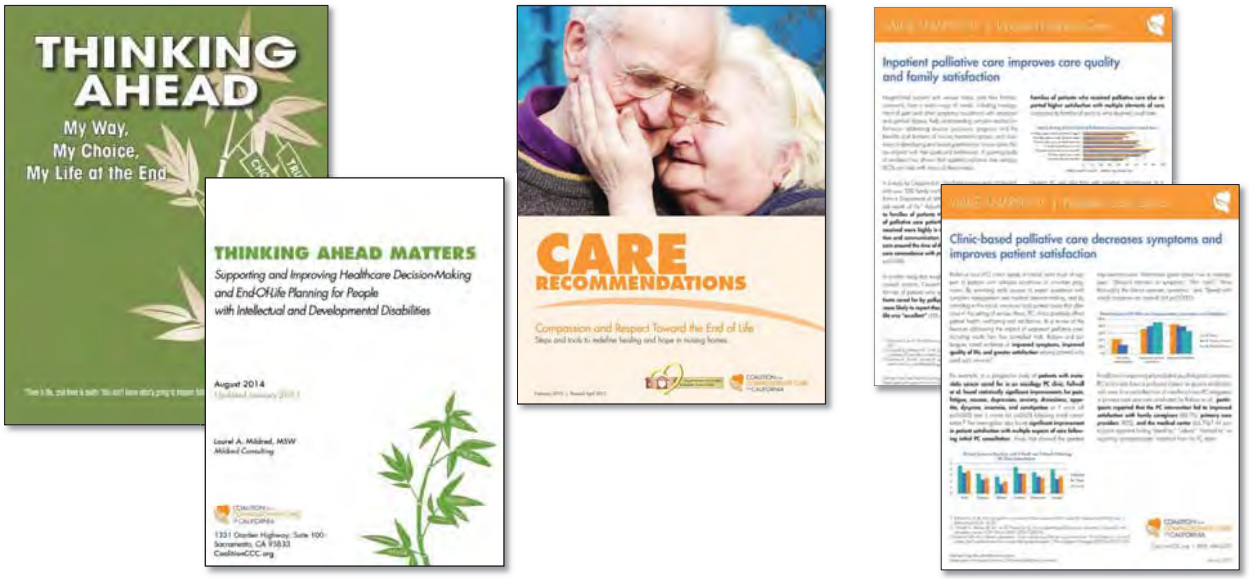
Resources



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Video Resources

A few video examples showing how Advance Care Planning can impact lives of patients and families (California Healthcare Foundation)

Reflections on End-of-Life Care: Honoring Wishes RAYMOND: http://www.youtube.com/watch?v=qvsXKMWPI-w

Reflections on End-of-Life Care: Not a Mind Reader MARIA: http://www.youtube.com/watch?v=SF4DORv_UYk

Reflections on End-of-Life Care: Death a Part of Life: http://www.youtube.com/watch?v=vSyiY5gxaCo

Reflections on End-of-Life Care: Listening to the Patient: https://www.youtube.com/watch?v=Os2mr2eVWTk

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City of Hope

Pain & Palliative Care Resource Center

www.cityofhope.org/prc

Resources for Caregivers

Helping yourself help others: A book for caregivers

Rosalynn carter with susan golant, 1994, times books, random house

Inspirations for caregivers

Caryn summers, RN, 1993 commune-a-key publishing

When helping you is hurting me: escaping the messiah trap

Carmen renee berry, 1988, harper and row publishers

Guide for cancer supporters

Annette and richard bloch, 1992, R.A. Bloch cancer foundation

The caregiver's book: caring for another, caring for yourself

James miller, 1996, augsburg fortress

New lifestyles: los angeles/ventura counties: An area guide to senior residences and care options (seasonal publication)

Available through (800) 869-9549

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Recommended Internet Resources

- http://www.cancercare.org/
- http://www.painfoundation.org/
- http://www.livestrong.org/
- http://www.stoppain.org/
- http://www.cityofhope.org/PRC/
- http://www.cancer.gov/cancertopics/understanding-cancer-pain
- http://www.cancer.gov/cancertopics/paincontrol
- http://www.nccn.org/patients/patient_gls/_english/_pain/contents.asp

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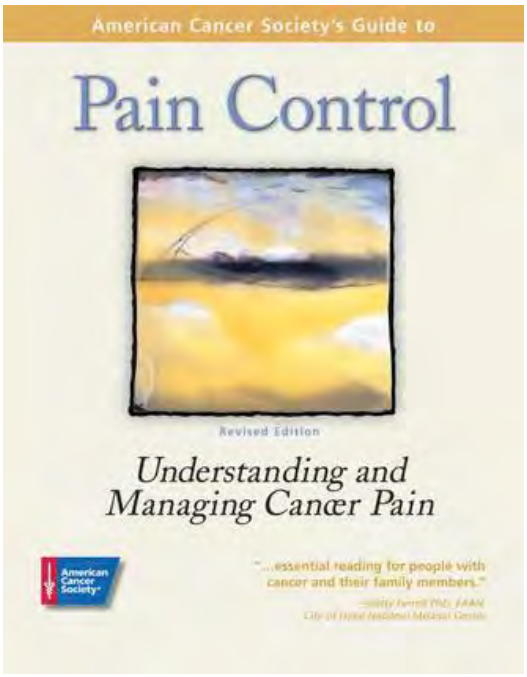

Effective pain management enables you to live the life you want to lead--to eat, sleep, spend time with loved ones, work, pursue hobbies, and take part in other activities. *The American Cancer Society's Guide to Pain Control* explains the many pain-relief options available, including medicines and other methods. Inside, you will discover how to achieve acceptable pain control and how to understand the optimal balance between pain relief and the potential side effects of pain medications.

NCCN Pain Guidelines

- http://www.cancer.org/downloads/CRI/NCCN_Pain_II.pdf
- http://www.nccn.org/professionals/physician_gls/PDF/pain.pdf

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My Goals:

In this workshop, I hope that we might…

- Understand the importance of a biopsychosocial-spiritual model of care
- Why a multidimensional assessment of suffering by a skilled interprofessional team is needed to most effectively manage pain and suffering at end of life
- Explore strategies to enhance our delivery of pain and symptom management

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Questions, Comments Next Steps?

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