

Palliative Care Symptom Management

THINKING OUTSIDE OF THE BOX

A solid orange horizontal bar at the bottom of the slide.

Symptom Management and Goals of Care Conversations

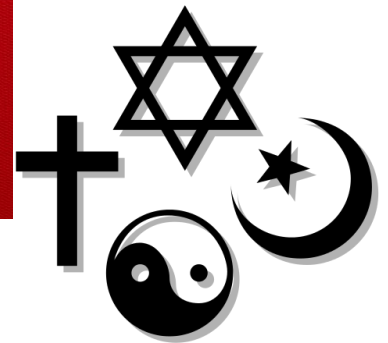


When Medicine and Conversation are not enough.....

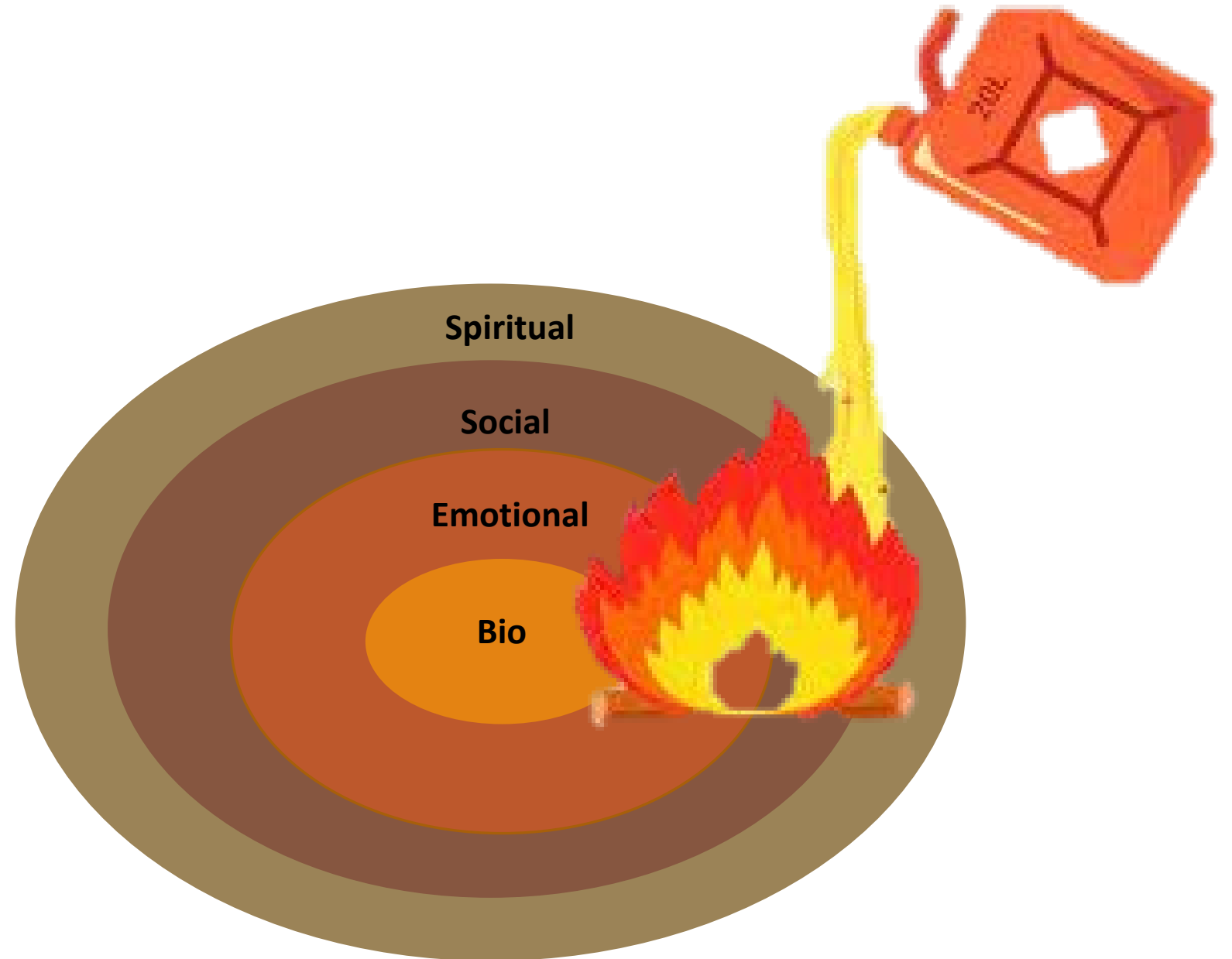


Pain
Nausea
Shortness of
Breath
Constipation

Ventilators
Chemotherapy
Hospice
Feeding tubes
CPR



Total Pain:
*Gasoline
on Fire!*





Spirituality vs. Religion

Spirituality is *“the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.”*

*National Consensus Project for Quality Palliative Care
(2009)*

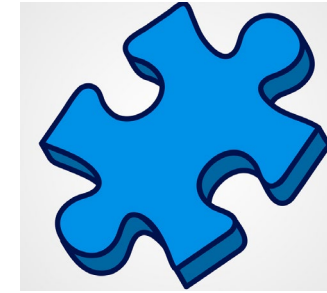
Religion is a formalized way of expressing spirituality.

Spiritual Needs: Four Dimensions

- Meaning
- Transcendence
- Values
- Psycho-Social Identity



Meaning

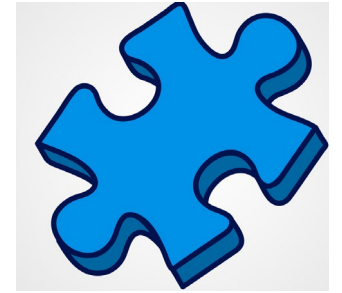


Loss of the Assumptive World



Kushner, Harold s; *The Book of Job: When Bad Things Happened to a Good person*; Schocken; 1 edition (October 2, 2012)

Meaning-The Need for Equilibrium



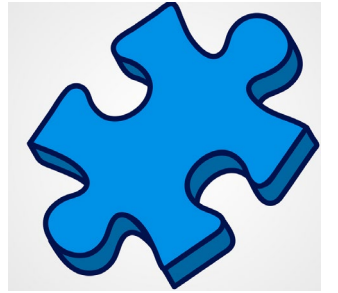
Distress

- “This doesn’t make any sense”
- “This isn’t fair”
- “There is no way I will be able to get through this”
- COVID



Meaning = Equilibrium

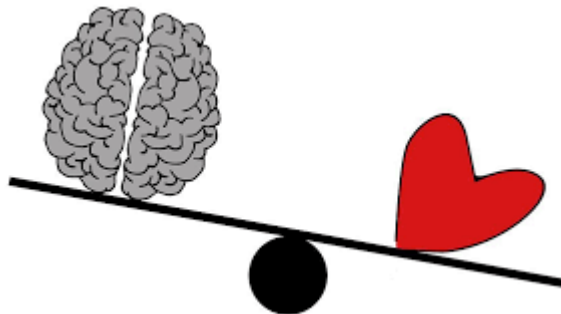
What do you do when they don't "get it"



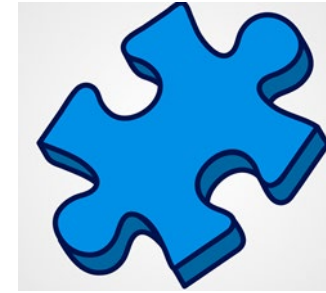
- Understand that medicine makes meaning with what they **see** and what they can **measure**



- Patients/families often make meaning with their **hearts**



Meaning: Regaining balance



- Name the issue!
- Affirm their heart
 - “This isn’t fair”
 - “This is overwhelming”
 - “You will never be ready to say goodbye”



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Transcendence: The Need for Connection



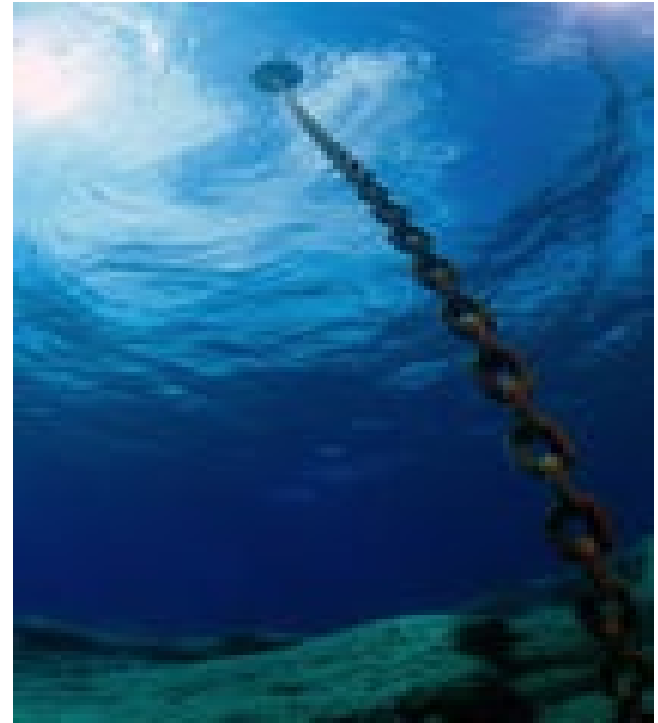
- The need for connection with an existential foundation that provides a sense of grounding
- The need for Beauty (aesthetic sense)



Transcendence/Connection: Your Anchor

Each person is individual:

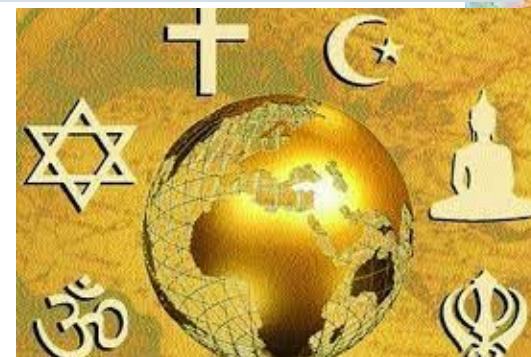
- Religion
- Music
- Animals
- Family
- The Beach
- Gardening
- Sports





Use your team for symptom control!

- What do you already know?
 - FICA
 - Faith
 - Importance/Influence
 - Community
 - Address/Action
- Music
 - Encourage families to create a playlist
- Animals
 - “Getting your fingers in some fur”
- Art therapy
- Photos
 - Items from home



Potential Signs of Distress

“I have nothing to hold on to”

“I just can't seem to paint anymore”

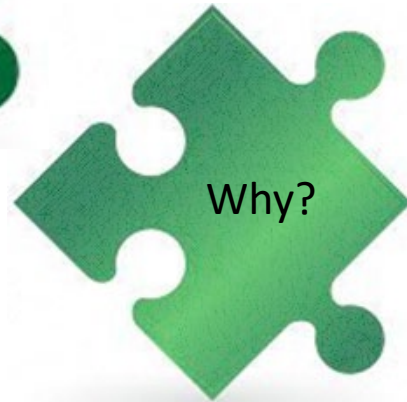
“I have always gone to church and now I think that must have been a waste of time.”

“My community (my family) has abandoned me”





Transcendence Question: From Why? To Where?



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Values: Two Components



Need for values acknowledgement

- Feeling that what is important to you is truly seen and understood by others

Need to maintain control

- The ability to determine and live out what matters to you



Values :

Acknowledgement and Control

Need for values acknowledgement

- “I’m just a number here. The staff doesn’t know who I am.”
- “Why do they keep on talking about negative things?”
- “I’m just a widget on a conveyor belt”

Need to maintain control

- “I don’t know what I’m doing here in the hospital.”
- “Why hasn’t anyone given me any medicine?”

Nurturing Relationship



- ❑ Acknowledgement
 - ❑ Repeat and rephrase their concern
 - ❑ “What I hear you saying is.....”
 - ❑ “I am hopeful too, but I also know you don’t want me to sugarcoat the medical information”
- ❑ Control
 - ❑ Give them something to control
 - ❑ What do you need right now that I can help with?
 - ❑ GOC “baby steps”
 - ❑ Plant seeds
 - ❑ “We are talking about this right now because things are calm
 - ❑ You don’t need to think about this/make a decision right now



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Psychosocial Identity

The Need to maintain identity

My friends don't know what to say to me

"My family has no idea of what I'm going through"

"I've always been the one who took care of everyone else"

"I don't usually act like this. This isn't who I am."



Psycho-Social Identity: Stereotype



Old

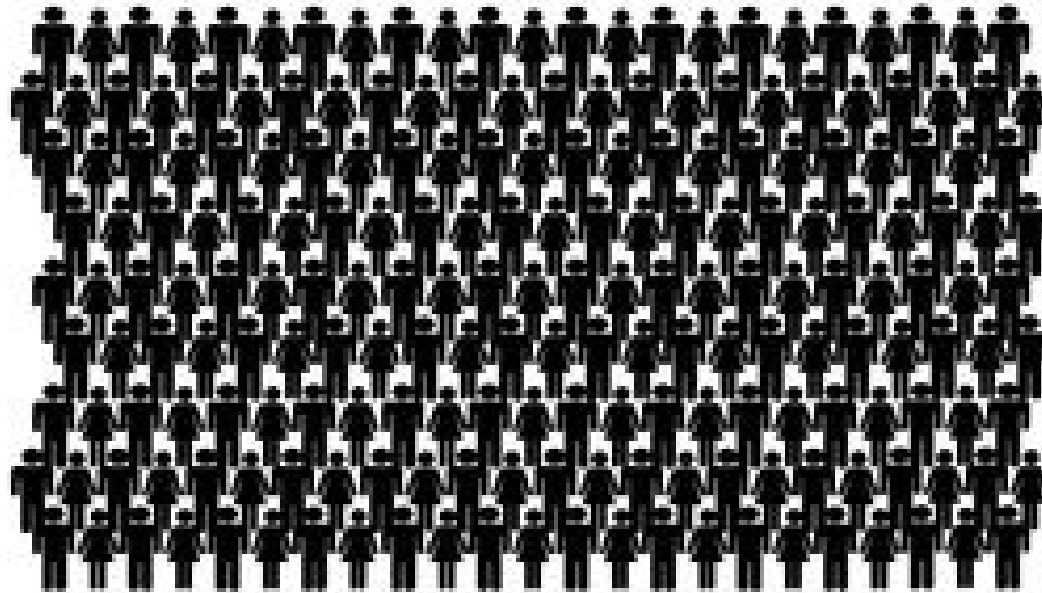
Needy

Burdensome

Sad

Dependent

Life is over



Stupid

Selfish

Unworthy

Weak

Cowardly

Helpless

Name the Unchanging Essence



Reframe Labels

- Matriarch
- Musician
- Lawyer
- Athlete
- Friend

Celebrate Interdependence

- Care for others by allowing them to care for you





Who has time for the patient who:



has the same looping conversations

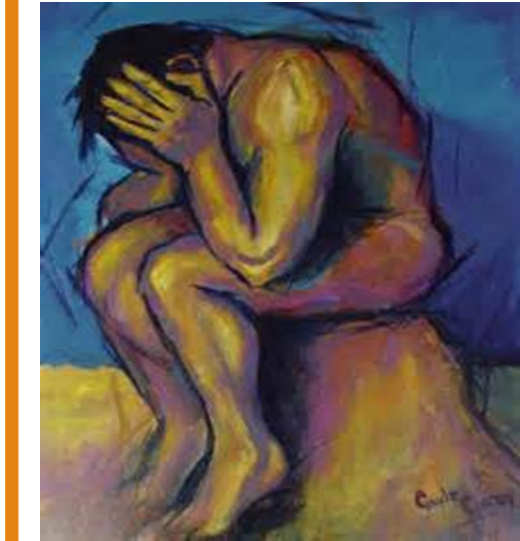
is always complaining

Is non-compliant

Is in denial

All behavior has a function:
Save Time by looking behind the
behavior and put the puzzle
together





Compassion: To Journey “with”

“Who is there in all the world who listens to us? Here I am – this is me in my nakedness, with my wounds, my secret grief, my despair, my betrayal, my pain which I can’t express, my terror, my abandonment. Oh, listen to me for a day, an hour, a moment, lest I expire in my terrible wilderness, my lonely silence. Oh God, is there no one to listen?”



No one left alone

Good Palliative Care

- Transdisciplinary vs. Interdisciplinary
- Cross training
- Everyone should be looking for all dimensions of distress



An Affirmation For Those Who Care

I believe in people who care.

Even more, I believe in what these generous people offer others.

They bring caregiving down to its essentials:

they offer not abstract ideas, but personal attention;

not definitive answers, but reasonable assurance;

not empty platitudes, but authentic hope.

Because such committed caregivers are among us,

we know the world is not just a better place

but ours is a better time and we are a better people.

We know that because those who truly care show us,
day after day after day.

