



# IAPCON 2025

## 32<sup>nd</sup> International Conference of the Indian Association of Palliative Care (IAPC)

30<sup>th</sup> Jan 2025 -Pre Conf. Workshop | 31<sup>st</sup> Jan - 2<sup>nd</sup> Feb, 2025-Conference | AIIMS, Jammu

Organized by: J&K chapter of IAPC and All India Institute of Medical Science, Jammu.

## We the Tool – Spiritual Assessment



**“Doctor” 1891 :: 2011**

*Cognizant of of ‘Mutual’ listening*

## ‘WE’ the Tool

What qualities of this person made you think of her/him?

Exercise: think of a person who you would want around ...When you go through a personal crisis...

# Therapeutic presence

Know all the theories, master all the techniques, but as you touch a human soul be just another human soul.

CARL JUNG



- Value the therapeutic relationship

*“The real presence of another person is a place of security. We have to give all patients that feeling of security in which they can begin, when they are ready, to face unsafety.”*

*Unconditional, non-judgemental presence*

The Namasthe of Caring Framework to identify, evaluate  
Spiritual Distress

# Spiritual Assessment



**'WE' the Tool**

# 'WE' LISTEN

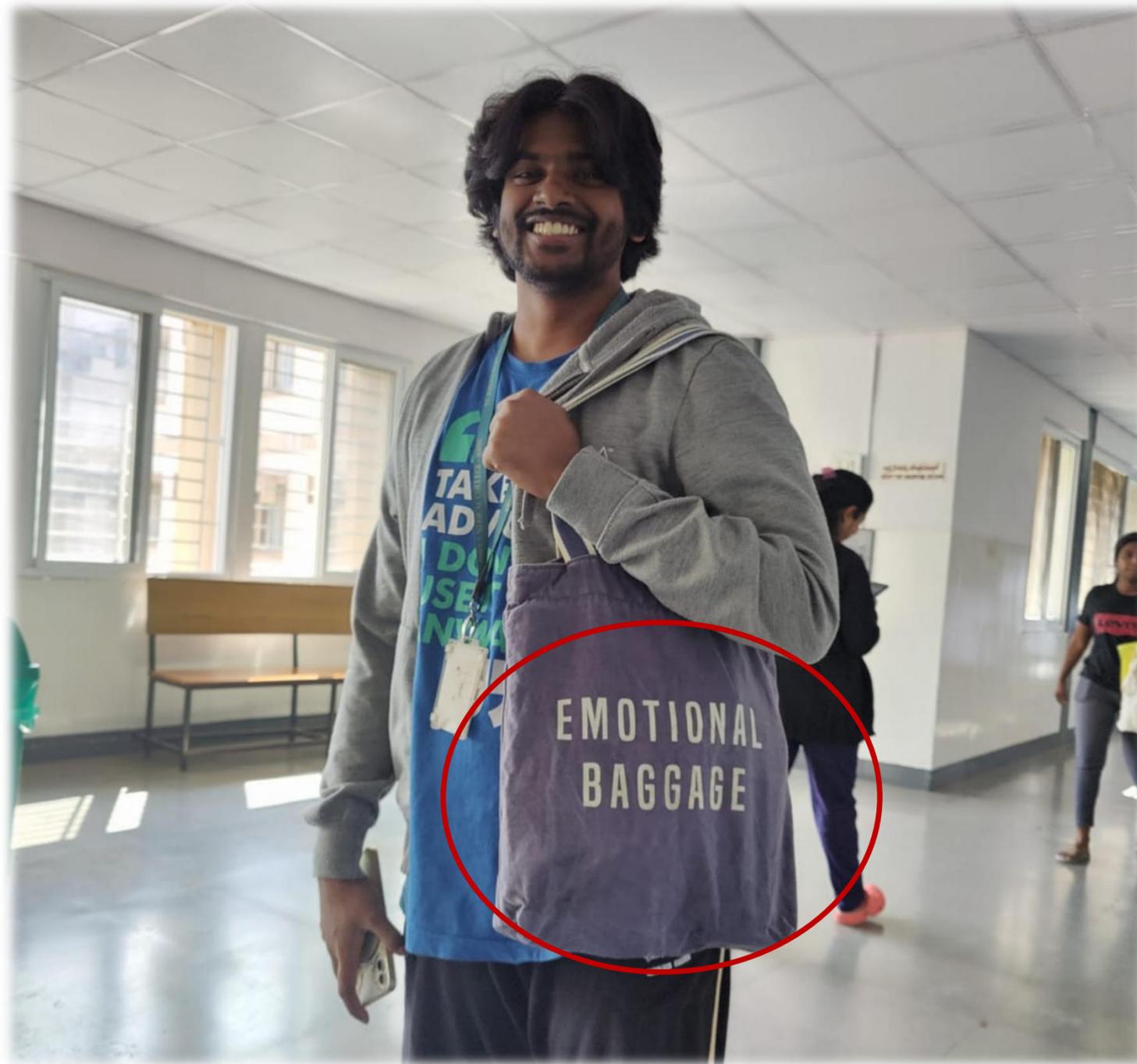
Sit

Am I fully present here?  
Calm and settled; relaxed,  
straightened back, feet on  
the floor.... Aware of HERE

Maintain Eye  
contact

Lean forward

Unconditional, non-judgemental presence



# WE use our Communication Skills & Tools

- Preparedness, Self-awareness
  - G R A C E: Gather, Reflect, Attune, Consider what'll serve, Explore
- Use active LISTENing
  - Ask - Tell – Ask and NURSE
  - Opening ASK
    - How have you been dealing with all that is going on?
    - What has helped you get through these difficult times?
  - TELL
    - Validate whatever that is being done
  - ASK
    - Would you tell me more about....?                      Continuer / Terminator responses
- Express Empathy
  - NURSE: Name Understand, Respect, Support, Explore

# WE Listen to: Direct expressions of Spiritual Suffering

- Why me, why now?
- What is the purpose of such a life? I don't see any reason to live
- Regret: I should've ... shouldn't have
- Persecution: Do I deserve be in this state??
- It's better to die than live like this

# WE Listen to: Indirect expressions of Spiritual Suffering

## Physical

- Intractable pain, difficult-to-treat symptoms,
- Low functional score

## Psychological

- Disproportionate anger, anxiety, depression, bargaining, hopelessness, fear
- Too many questions, too few questions

## Social

- Conflicted relationships, withdrawn/ isolated, afraid to sleep...of being alone

## Communications

- Avoiding eye contact, refuse care, violent, silent, irrational bargaining, extreme responses

# TOOLS

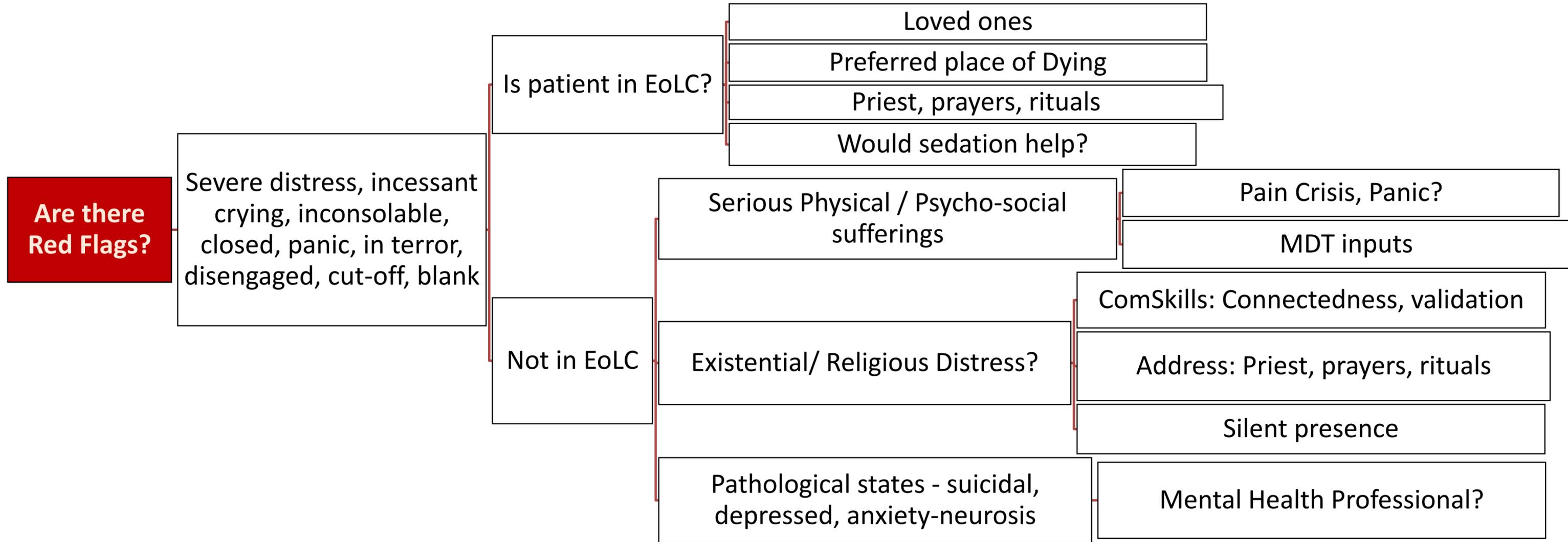
- ‘WE’ ARE the Tool
  - ....then, there are tools that WE may use

# Simple screening questions

- How are you coping with this illness? What's been most helpful for you to cope?
- Commonly we see patients questioning the meaning of what's happening.... ..how about you?
- Have your religious practices changed with your health condition? (Excessive religiosity)
- Has Religion / Spirituality become prominent, as you cope with your illness?
- Are there important religious practices that are for us to be aware of, as we care for you?

# ASK – TELL - ASK

## CAN YOU TELL ME MORE...?





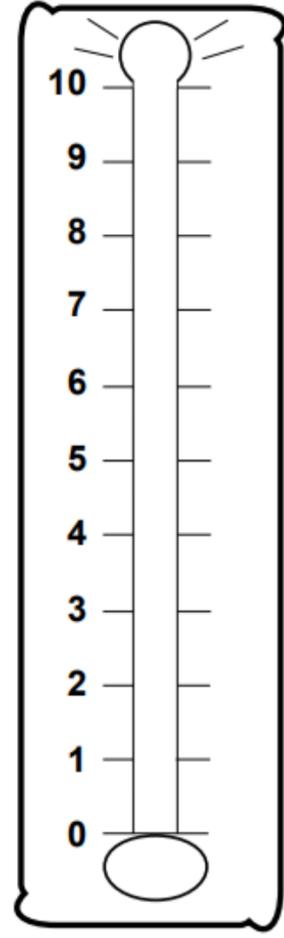
# NCCN Guidelines Version 2.2023 Distress Management

## NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress



No distress

## PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

### Physical Concerns

- Pain
- Sleep
- Fatigue
- Tobacco use
- Substance use
- Memory or concentration
- Sexual health
- Changes in eating
- Loss or change of physical abilities

### Emotional Concerns

- Worry or anxiety
- Sadness or depression
- Loss of interest or enjoyment
- Grief or loss
- Fear
- Loneliness
- Anger
- Changes in appearance
- Feelings of worthlessness or being a burden

### Social Concerns

- Relationship with spouse or partner
- Relationship with children
- Relationship with family members
- Relationship with friends or coworkers
- Communication with health care team
- Ability to have children

### Practical Concerns

- Taking care of myself
- Taking care of others
- Work
- School
- Housing
- Finances
- Insurance
- Transportation
- Child care
- Having enough food
- Access to medicine
- Treatment decisions

### Spiritual or Religious Concerns

- Sense of meaning or purpose
- Changes in faith or beliefs
- Death, dying, or afterlife
- Conflict between beliefs and cancer treatments
- Relationship with the sacred
- Ritual or dietary needs

### Other Concerns:

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# FACIT Sp-12 Version 2- Assess spiritual health / distress

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Some-what	Quite a bit	Very much	
Meaning/Peace	Sp1	I feel peaceful .....	0	1	2	3	4
	Sp2	I have a reason for living .....	0	1	2	3	4
	Sp3	My life has been productive .....	0	1	2	3	4
	Sp4	I have trouble feeling peace of mind .....	0	1	2	3	4
	Sp5	I feel a sense of purpose in my life .....	0	1	2	3	4
	Sp6	I am able to reach down deep into myself for comfort .....	0	1	2	3	4
	Sp7	I feel a sense of harmony within myself .....	0	1	2	3	4
	Sp8	My life lacks meaning and purpose .....	0	1	2	3	4
Faith	Sp9	I find comfort in my faith or spiritual beliefs .....	0	1	2	3	4
	Sp10	I find strength in my faith or spiritual beliefs .....	0	1	2	3	4
	Sp11	My illness has strengthened my faith or spiritual beliefs .....	0	1	2	3	4
	Sp12	I know that whatever happens with my illness, things will be okay .....	0	1	2	3	4

For patients 18 years and older

<https://www.facit.org/measure-english-downloads/facit-sp-12-english-downloads>

- The spiritual distress score is 1 for sahamat (सहमत)/agree and 0 for asahmat (असहमत)/disagree.
- Neutral responses (निरपेक्ष) are not coded and are not considered
- The mean score of all X by 100, exclude neutral responses

**The outcome will be a score between 0 and 100.**

**SpiDiSci-PC (Spiritual Distress Scale for Palliative Care in India)**

Please indicate the extent to which the patient agrees or disagrees with the following statements ticking the corresponding box. Ask the patient to answer in accordance with how he or she felt over the last two weeks. The neutral response is not to be presented as a standard answer category to the patients. It should only be used when patients, for whatever reason, find it impossible to either agree or disagree with a statement.

		Agree	Neutral	Disagree
1	Since the onset of my illness, I have become less interested in thinking about God or religion.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	I wonder why this illness has happened to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	I find it difficult to forgive others for wrong they did to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	This illness is unfair.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	I wonder what will happen after death.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	I am afraid of the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	I feel lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Since the onset of my illness, I have become less interested in hearing about God or religion.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	When I think of God, I feel agitated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Because of my illness, I find it difficult to do puja or other religious rituals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	My illness or pain is a punishment for wrong done by me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Thinking about what will happen after death frightens me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	God has abandoned me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Due to my illness, I have lost faith in a higher benevolent power.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Since the onset of my illness I am wondering more often whether my decisions are good and right.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	I find it difficult to forgive myself for wrong I did.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**भारतीय पैलीअटिव केर के लिए आध्यात्मिक चिंता का स्केल**

कृपया निम्नलिखित कथनों से रोगी के सहमत अथवा असहमत होने की सीमा को संबंधित बॉक्स में चिन्हित करके दर्शित करें। रोगी को पिछले दो सप्ताह के दौरान उसके क्या अनुभव किया इस पर उसे प्रश्नों का उत्तर देने के लिए कहें। मरीजों को निरपेक्ष का जवाब सामान्य जवाब जैसे अनुभाव मत करा दियें। उस जवाब को सिर्फ तभी चुना जा सकता है जब मरीज किसी भी कारण से उसी कथन में सहमत अथवा असहमत नहीं हो सकता है।

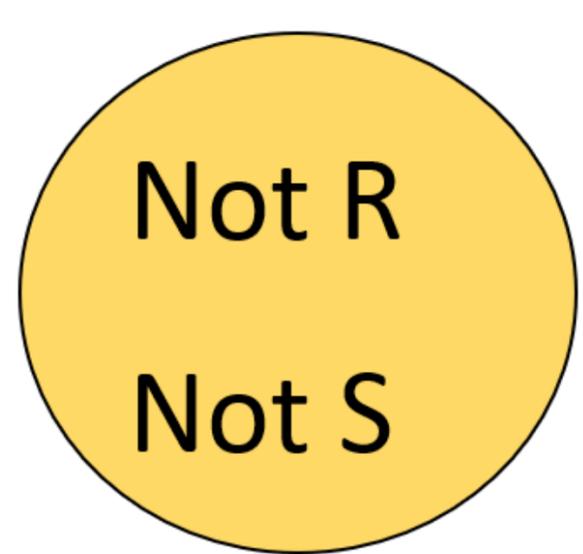
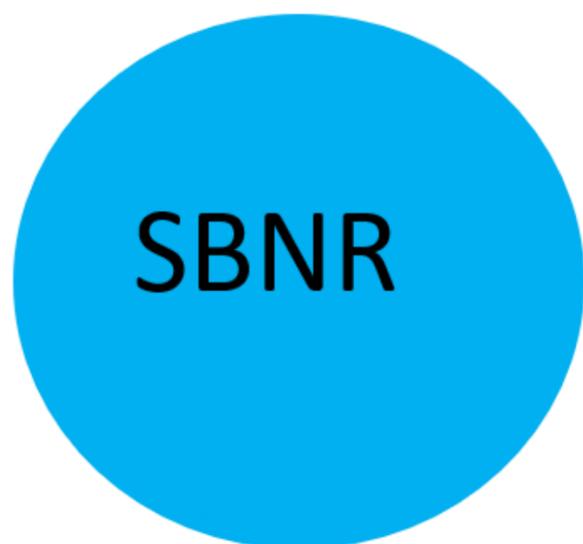
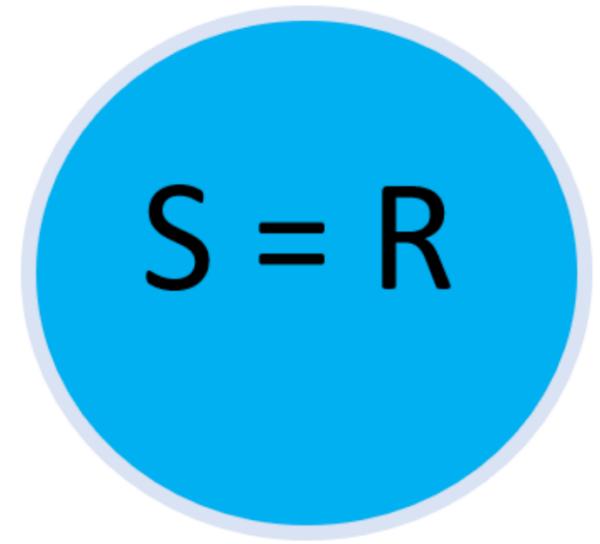
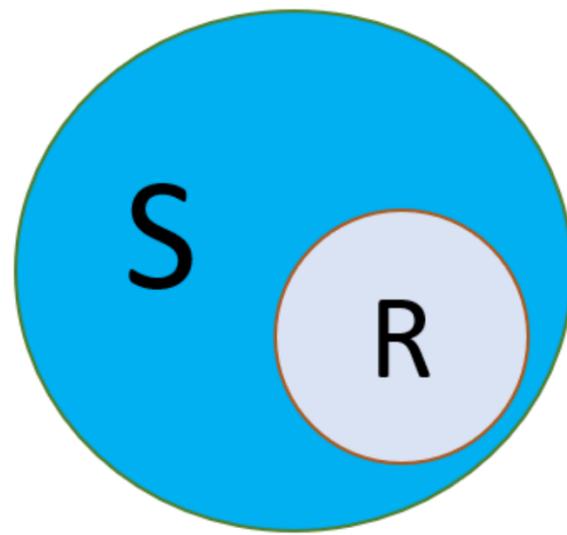
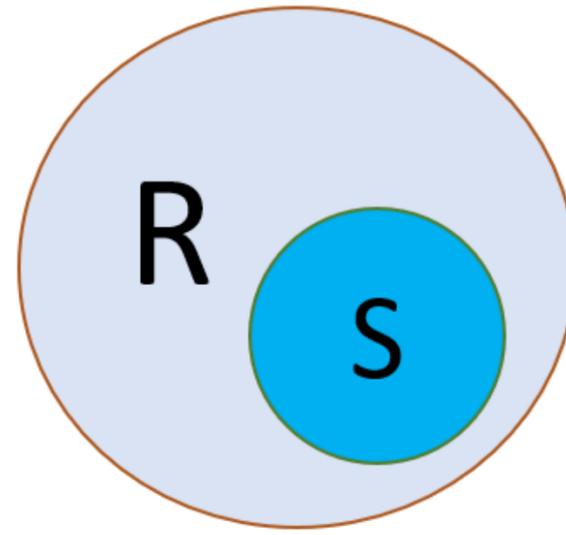
		सहमत	निरपेक्ष	असहमत
1	जबसे मैं बीमार हुआ हूँ, तबसे ईश्वर/अल्ला या धर्म के प्रति मेरी रुचि कम हो गई है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	मैं हैरान हूँ कि यह बीमारी मुझे क्यों हुई।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	दूसरों ने जो मेरे साथ गलत किया उसके लिए मुझे उन्हें माफ करने में कठिनाई होती है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	यह बीमारी अन्याय है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	मुझे आश्चर्य होता है कि मरने के बाद क्या होगा।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	मैं भविष्य से डरता हूँ।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	मुझे अकेलापन अनुभव होता है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	जबसे मैं बीमार हुआ हूँ तबसे, मुझे ईश्वर/अल्ला या धर्म के संबंध में सुनना इतना पसंद नहीं है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	जब मैं ईश्वर/अल्ला के संबंध में सोचता हूँ तो अशान्त हो जाता हूँ।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	अपनी बीमारी के कारण मुझे पूजा या अन्य धार्मिक कार्य करने में कठिनाई होती है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	मेरी बीमारी या पीड़ा, मेरे किसी पाप की सजा है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	मृत्यु के पश्चात् क्या होगा यह सोचकर मुझे डर लगता है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	ईश्वर/अल्ला ने मुझे छोड़ दिया है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	बीमारी के कारण, मेरा सबसे बड़ी शक्ति पर से विश्वास उठ गया है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	जबसे मुझे बीमारी हुई है, मुझे आश्चर्य रहता है कि मेरे पास सही है या गलत।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	मुझे अपने गलत किए गए कार्यों के लिए स्वयं को माफ करने में कठिनाई होती है।	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# HOPE: Assess spiritual health / distress

- **H:** Sources of hope, strength, comfort, meaning, peace, love & connection
- **O:** Role of organized religion for the patient
- **P:** Personal spirituality and practices
- **E:** Effects on medical care and end-of-life decisions

# FICA Tool: To assess Religious / spiritual support

- **F**aith or beliefs
  - What is your faith or belief?
- **I**mportance and influence
  - What role do your beliefs play in influencing your health?
- **C**ommunity
  - Are you part of a spiritual community?
- **A**ddress
  - How should these issues be addressed by the health care provider?



# Exercises

Group 1: What are the expressions / phrases used by patients when in religious Distress?

Group 2: What are the positive and negative Expressions of Religious Distress and Coping

# Expressions of Distress (God/ Religion)

- Am I being punished?
- I deserve to have this pain, maybe it'll cleanse my sins!
- Will I be saved by changing into this new religion? Can this new God cure me?
- I am tormented with thoughts of eternal hell....Will I get redemption /salvation...?
- Why this terrible disease!...people will laugh at my faith in God. They will label me as a fraud!
- God... I am unable to reach you !.....I'm unable to even sit down to pray because of this severe pain (foul smelling wound)

# Religious Expressions of Distress and Coping

## Positive

- Stronger connection with God
- Talks about Gods love and care
- Seeking help, gaining strength
- Emotional stability in relationships, behaviour

## Negative

- Feeling abandoned by God
- Feeling punished by God
- Questions own belief-system
- Questions God's presence, & power

R/S struggle maybe underestimated, when spiritual > religious or have existential concerns as opposed to theistic concerns.

1. Do you struggle with the loss of meaning and joy in your life?
2. Do you currently have what you would describe as religious or spiritual struggles?

*not at all, somewhat, quite a bit, great deal*

- Steinhauser et al: Are you at peace?

*not at all, little bit, moderate amount, quite a bit, completely*

Ref: S King et al: Support Care Cancer (2017) 25:471–479

## Religious Struggle Screening Protocol

# Religious Struggle Protocol

## Revised RUSH Protocol

❶ Is religion or spirituality important to you as you cope with your illness?

**YES**

❷ How much strength/comfort do you get from your religion/spirituality right now?

- a) all that I need  
▶ For A, go to Question 3
- b) somewhat less than I need
- c) none at all  
▶ For either B or C, thank patient & check #3 on follow-up

❸ Would you like a visit from a chaplain?

**YES**

Thank patient & order chaplain visit

**NO**

Thank patient for their time

**NO**

❹ Has there ever been a time when religion/spirituality was important to you?

**YES**

Thank patient & order spiritual assessment

**NO**

❺ Would you like a visit from a chaplain?

**YES**

Thank patient & order chaplain visit

**NO**

Thank patient for their time

**Table 2. The Brief RCOPE: Positive and Negative Coping Subscale Items.**

***Positive Religious Coping Subscale Items***

1.	Looked for a stronger connection with God.
2.	Sought God's love and care.
3.	Sought help from God in letting go of my anger.
4.	Tried to put my plans into action together with God.
5.	Tried to see how God might be trying to strengthen me in this situation.
6.	Asked forgiveness for my sins.
7.	Focused on religion to stop worrying about my problems.

***Negative Religious Coping Subscale Items***

8.	Wondered whether God had abandoned me.
9.	Felt punished by God for my lack of devotion.
10.	Wondered what I did for God to punish me.
11.	Questioned God's love for me.
12.	Wondered whether my church had abandoned me.
13.	Decided the devil made this happen.
14.	Questioned the power of God.

Pargament, K., et al. (2011). The Brief RCOPE: Current Psychometric Status of a Short Measure of Religious Coping. *Religions*, 2(1), 51-76.

# AMEN Tool

Original Contribution

## AMEN in Challenging Conversations: Bridging the Gaps Between Faith, Hope, and Medicine

By Rhonda S. Cooper, MDiv, BCC, Anna Ferguson, RN, BSN, Joann N. Bodurtha, MD, MPH, and Thomas J. Smith, MD, FACP, FASCO, FAAHPM

The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore, MD

### Abstract

All health care practitioners face patients and families in desperate situations who say, "We are hoping for a miracle." Few providers have any formal training in responding to this common, difficult, and challenging situation. We

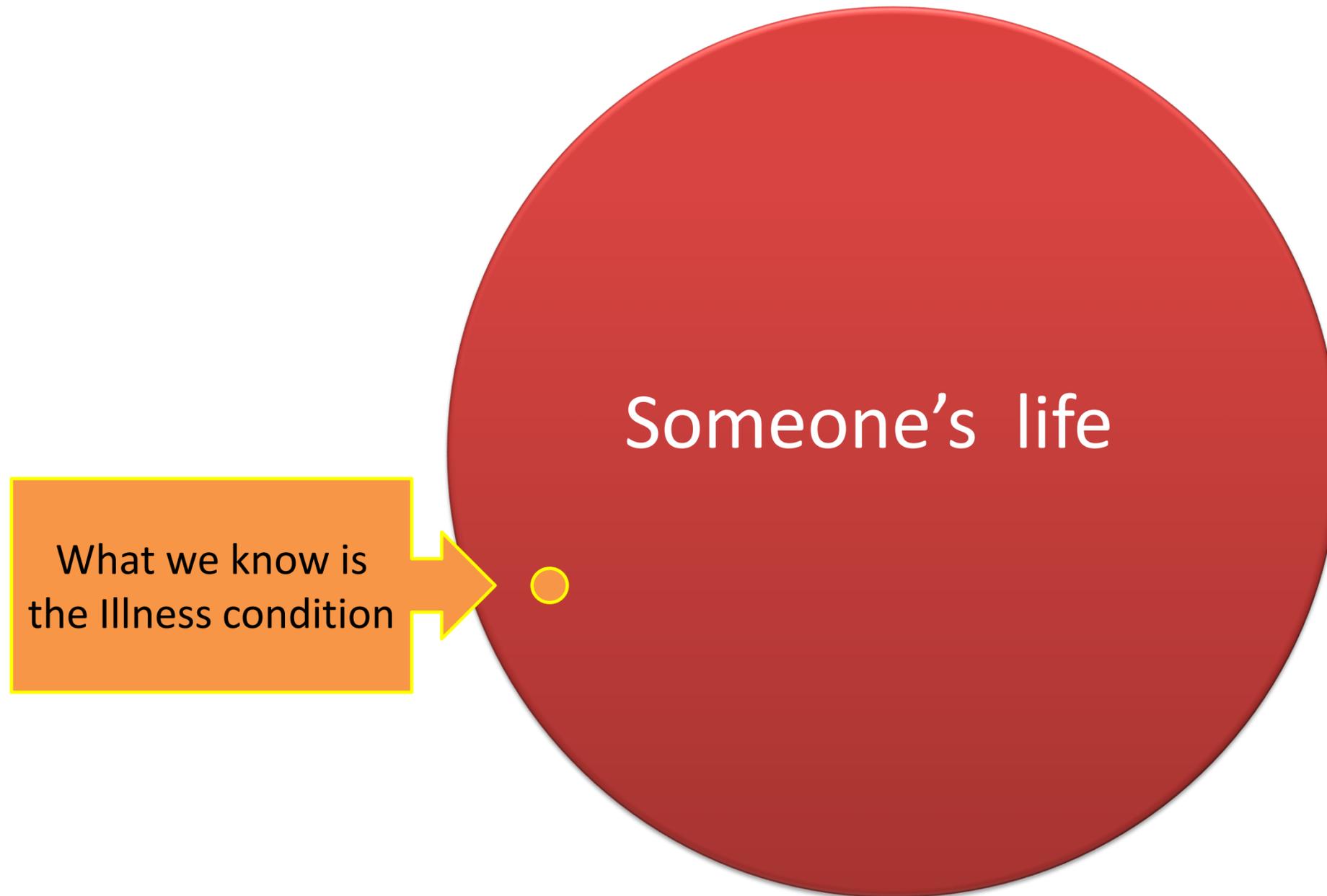
want to do our best to preserve hope, dignity, and faith while presenting the medical issues in a nonconfrontational and helpful way. We present the acronym AMEN (affirm, meet, educate, no matter what) as one useful tool to negotiate these ongoing conversations.

The heart of the AMEN protocol is the “and” ... the commitment to joining rather than placing more distance between patient and Dr .....Hope becomes the common ground for provider and patient

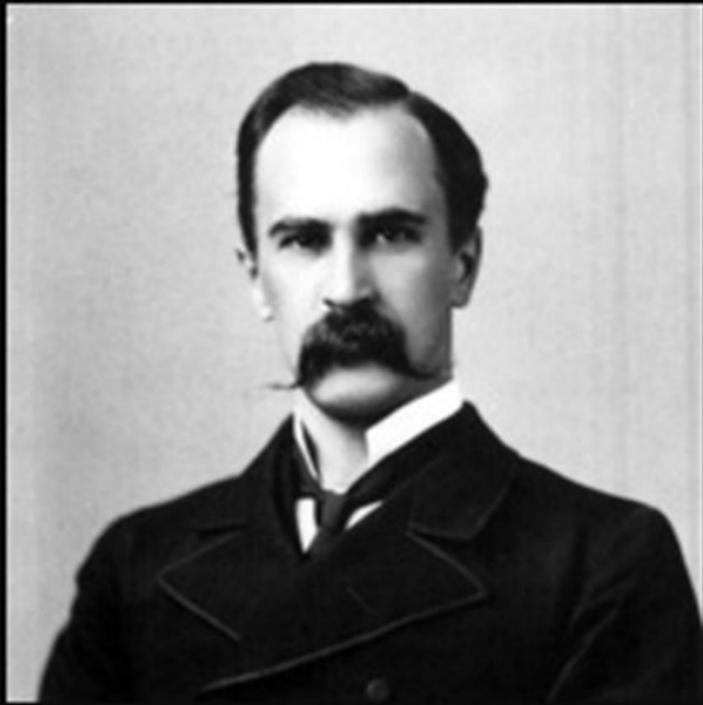
- **A:** Affirm the patient’s/family’s belief, provide validation of their position on miracles
  - ““I am hopeful too.”
- **M:** Meet the patient/family where they are emotionally/spiritually
  - “I support you in your prayers” “I will be glad to see you healed.”
- **E:** Educate from your position as a healthcare provider (nurse, doctor etc.)
  - “**And...** I want to talk to you about some medical issues.”
- **N:** No matter what ...assure the patient/family that you are committed to caring for them
  - “No matter what.... I will be with you every step of the way.”

•Ref: J Oncol Pract v.10(4); 2014 Jul

# Disclosure: Spiritual care is non- protocolisable



William Osler



It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.

AZ QUOTES



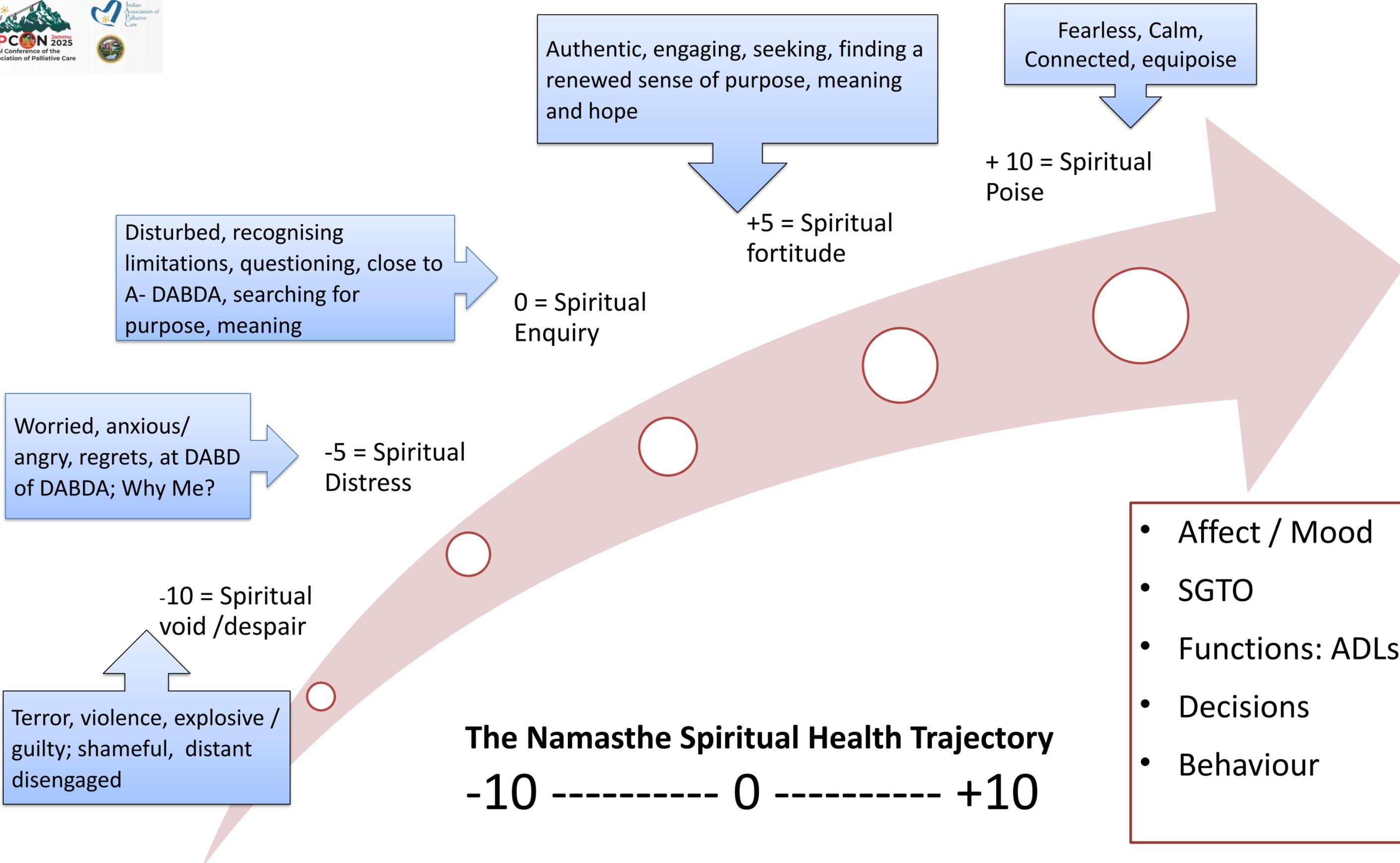
**The Namasthe Approach to managing Spiritual Suffering**

**Table – 1 The Namasthe Framework to help decide the Trajectory of Spiritual Health / Ill-Health**

<b>Attributes</b>	Sp. Poise: + 10	Sp. Fortitude: +5	Sp. Enquiry: 0	Sp. Distress: -5	Sp. Void: -10
<b>Affect / Mood</b>	Calm, Connected, Fearless, confident	Open, Positive, curious	Variable. May be anxious, worried; At risk of escalating anxiety, and worsening distress	distressed, crying, restless, suffering, confused, anxious Angry, conflicted, fearful about future	Frightened, terror, panicky, violent, explosive; OR Silent, numb, guilt, shame, distant, disengaged
<b>Functions</b>	Functionality as much as the physical condition allows Able to rest / sleep	Functionality as much as the physical condition allows Able to rest / sleep	Functionality less than what physical condition allows. Variable ability to rest / sleep	Functionality far less than what physical condition allows. Unable to rest / sleep	Functions disproportionately poor / nil to the physical condition Unable to rest / sleep
<b>Psycho-cognitive capacity</b>	Self-reflective, clear thinking Handling concerns as they arise Able to include welfare of others Feels validated about lived life	Self-reflective, curious, questioning, re-navigating hope Able to articulate and express concerns Feels validated about lived life	Unanswered questions on meaning and purpose of what’s happening, needs support to navigate through the adversity; Struggling with the situation. Overthinking, pre-occupied, Seeking validation	May not articulate the distress clearly Symptom control can be difficult due to pronounced psychological dimensions to the symptoms	Reclusive, rejects, avoids conversations Symptom control can be difficult due to pronounced psychological dimensions to the symptoms
<b>I-ness, personhood</b>	I-ness transcends ‘I, me, mine’ Self-aware, connected, moving forward accepting the situation and whatever that lies ahead Finds renewed meaning /purpose. Has sufficient resources to cope, face, and grow If religious – it continues to be an anchor	I-ness exceeds / transcends ‘I, me, mine’ Self-aware, exploring a renewed sense of personhood Trying to find meaning and purpose during/ following adversity Seeking resources to cope positively with the change. If religious, uses it positively, to cope with the change	I-ness at ‘I, me, mine’. May exceed ‘I, me, mine’ with personal growth Distresses connected to losing personhood (I-ness). Does not quite see meaning, purpose in life situation, searching for answers, solutions, If religious, may express hyper-religiosity, may hope for a miracle	I-ness at ‘I, me, mine’. Unable to accept the situation, regrets Sees no immediate meaning in life; mood may worsen with events If religious, may view it negatively (angry with God, shunning worship practices), OR may bargain for a miracle May get influenced to convert to another religion	I-ness at ‘I, me, mine’. Life feels meaningless, purposeless Sees no immediate meaning in life; mood may worsen with events
<b>Decisions</b>	Capacity to engage fully in discussions, and make informed autonomous care-decisions	Actively engaging with the team, family: able to connect their perspectives to bring clarity into the decisions	Listens, tries to engage with care-planning with questions, clarifying doubts. May find difficulty with decision-making	Ambiguous, unable to think clearly, or to participate in discussions, or for making decisions	Cognitively unavailable for discussions / decisions

# Spiritual fortitude

- The capacity for authentic engagement in the wake of hardship, along with sense of hope for finding a renewed sense of purpose and meaning
- It expresses as confidence in the face of a major stressor
- It reflects the spiritual depth in the person



- Affect / Mood
- SGTO
- Functions: ADLs
- Decisions
- Behaviour

