



# 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.

## Synopsis

# *My life no longer has any meaning....I am ready to die...*

- 19 years old Ms P from Asansol, 12<sup>th</sup> grade, aspiring musician, diagnosed with a very slow growing sacrococcygeal teratoma a year ago.
- She is bedridden with severe pain over right buttocks, burning, shooting in quality & radiating to the lower limb. Any movement causes pain. The power of her legs are intact.
- She has urinary retention and was using clean-self catheterisation technique to evacuate her bladder. Bowel sensations intact..
- She and her mother have been informed about the possibility of surgery to de-bulk the tumour and the need for colostomy. She is distraught, fearful.... but has no questions related to her condition.

It may be adept symptom Management & navigating decisions

Does this patient have spiritual concerns? If Yes, Specify the pointers to spiritual concerns  
How can we help Ms P in her distress?

# *My life no longer has any meaning....I am ready to die...*

- Mr P, 44-year-male, unmarried businessman, diagnosed with breast cancer with foul-smelling wound. He has not accepted treatment options right from the day of diagnosis
- He stays alone at present. His parents and one sister passed away over the last 3 years one after the other due to medical issues.
- He withdrew from friends and relatives, his interest in life is low, not engaging with work, his mood and energy levels was less than what was before. He feels very upset about taking help from others.

It may be treating depression, giving emotional support...being present

Does this patient have spiritual concerns? If Yes, Specify the pointers to spiritual concerns  
How can we help Mr P in his distress?

# *My life no longer has any meaning....I am ready to die...*

- Mr. S, 90 years, MA, Retired Government official. He has drastically altered his outlook towards life since last 15 years. His constant drive over these 15 years in following a spiritual journey which has been deeply satisfying to him.
- He had started limiting his food intake, avoided non vegetarian diet. He would often tell his family members 'my body is aging, I am preparing to leave when its fully worn out....'
- He was diagnosed to have cancer of transverse colon 1 year ago. He is aware of the diagnosis, and he continues his daily routines and life style as well as feasible.

It may be masterly co-travelling  
...supporting the natural flow of being

Does this patient have spiritual concerns? If Yes, Specify the pointers to spiritual concerns  
How can we help Mr S in his distress?



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## Outline

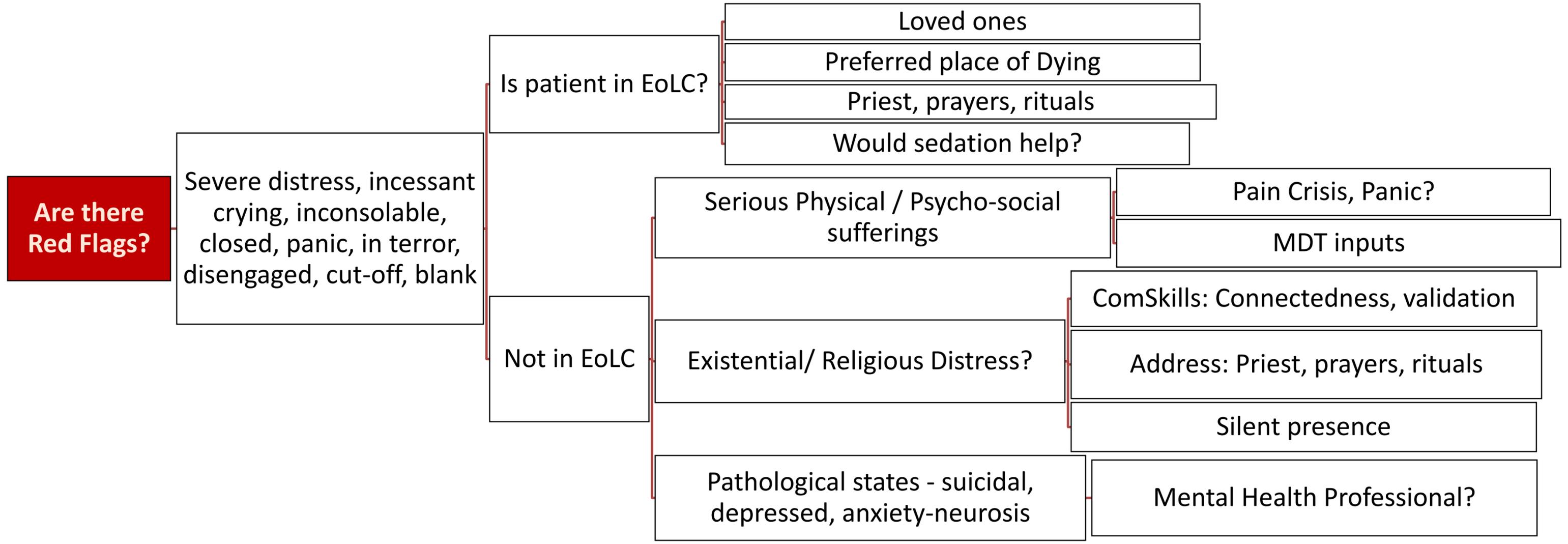
- What's this domain of spirituality?
- Where is this domain experienced?
- How does it manifest in our day-to-day life?
- Relevance & Challenges of Spiritual caring in Healthcare
- How do we provide Spiritual Care?

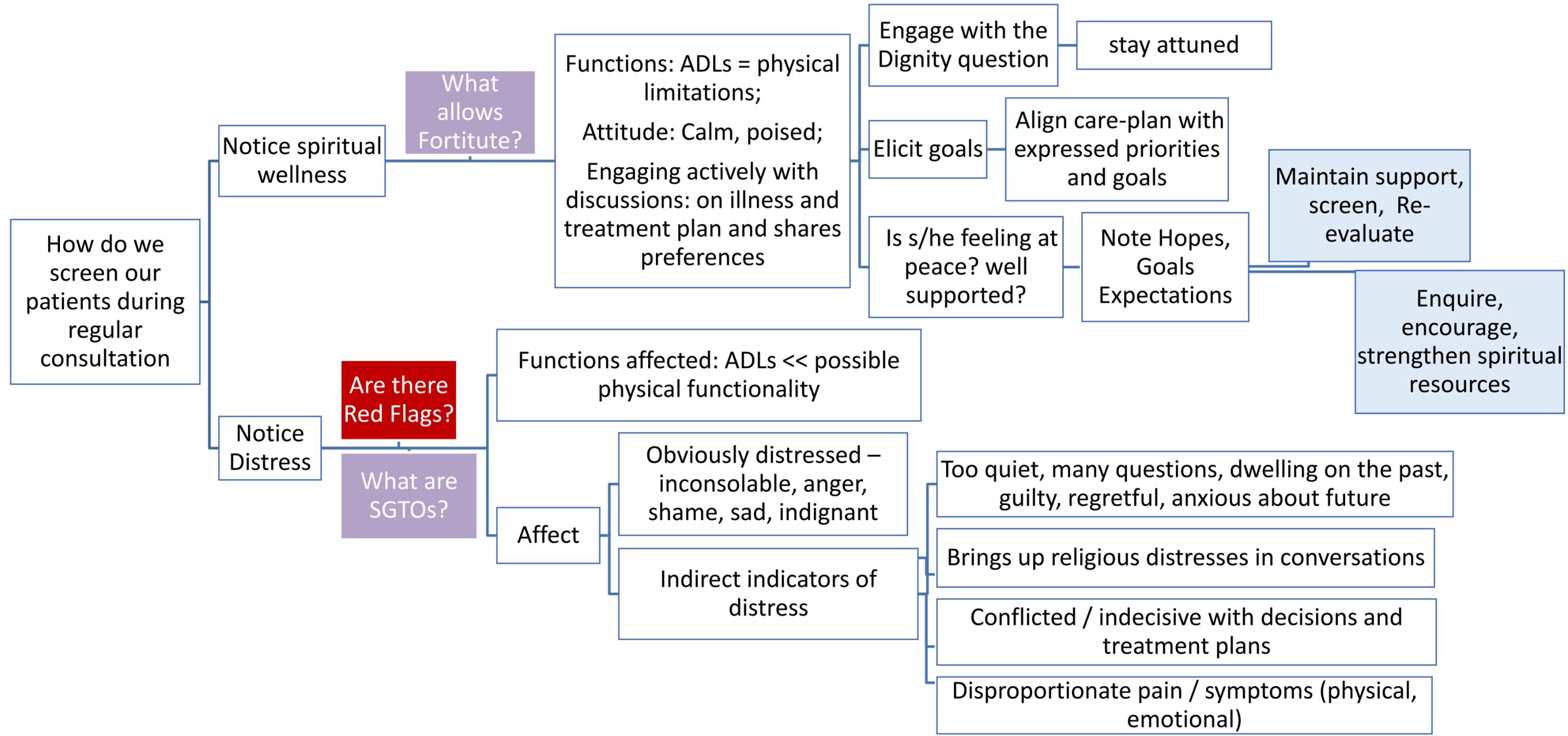
# Goals of Spiritual Caring

- Align with the patient's life-stance
- Listen deeply, for their preferences, strengths and resources
- Build therapeutic relationship
- Recognise, connect with their SGTOs to navigate care
- Aim: achieve a sense of meaning / balance / acceptance



**The Namasthe Approach to managing Spiritual Suffering**





# *The Namasthe Framework to help decide the Trajectory of Spiritual Health / Ill-Health*

Attributes	Sp. Mastery: + 10	Sp. Fortitude: +5	Sp. Reflective: 0	Sp. Distress: -5	Sp. Void: -10
<b>Affect</b>	Fearless, Calm, Connected, poised, seeing meaning /purpose  Feels validated about lived life	Positive, curious, hopeful of finding purpose and meaning during and following the adversity  Feels validated about lived life	Unanswered questions on meaning and purpose  Seeking connectedness, validation	Suffering; deeply distressed & anxious. Sees no immediate meaning in life  Conflicted, worried about future; mood swings	Terror, guilt, shame, violent, explosive, pleading .....OR Distant / disengaged from all / Silent
<b>SGTO</b>	Aware, strengthened with the SGTO, evolves to higher SGTOs  Complete acceptance on whatever that lies ahead	Aware, handling the change, finding a renewed sense of SGTO  Has sufficient resources to cope, face, and grow	Aware, distresses connected to the SGTO. Searching for solutions, Needs navigation  At risk of distress, difficulty to rest well, worried about unfinished business	Overthinking, pre-occupied with SGTO, escalating anxiety, worsening distress  Difficulty in accepting the situation, regrets	Difficult to elicit SGTO  Or in Panic regarding the SGTO
<b>Functions</b>	Functions & ADL as much as general condition allows	Functions & ADL as much as general condition allows	Functions & ADL as much as general condition allows	Functions & ADL << what general condition allows. Unable to rest / sleep	Poor/nil functions ADLs disproportionate to the general condition.
<b>Decisions</b>	Informed autonomous care-decisions	Actively engaging with the team, family: brings clarity into the decisions	Listens, tries to engages with care-planning with questions, clarifying doubts	Ambiguous, unable to think clearly, or make decisions	Cognitively unavailable for discussions / decisions
<b>Behaviour</b>	Able to include welfare of others; able to think, reflect, finds meaning & able to express, teach from self-experience	Open, reflective in thinking, questioning and trying to find meaning, answers	May shift to distress OR progress with acceptance – variable ability to rest / sleep	Distressed, angry; difficulty with symptom control; restless, OR zoning out, confused, quick to cry, not articulating the distress clearly, hopes for a miracle	Violent, inconsolable crying, suicidal, delirious OR Reclusive, rejects, avoids conversations

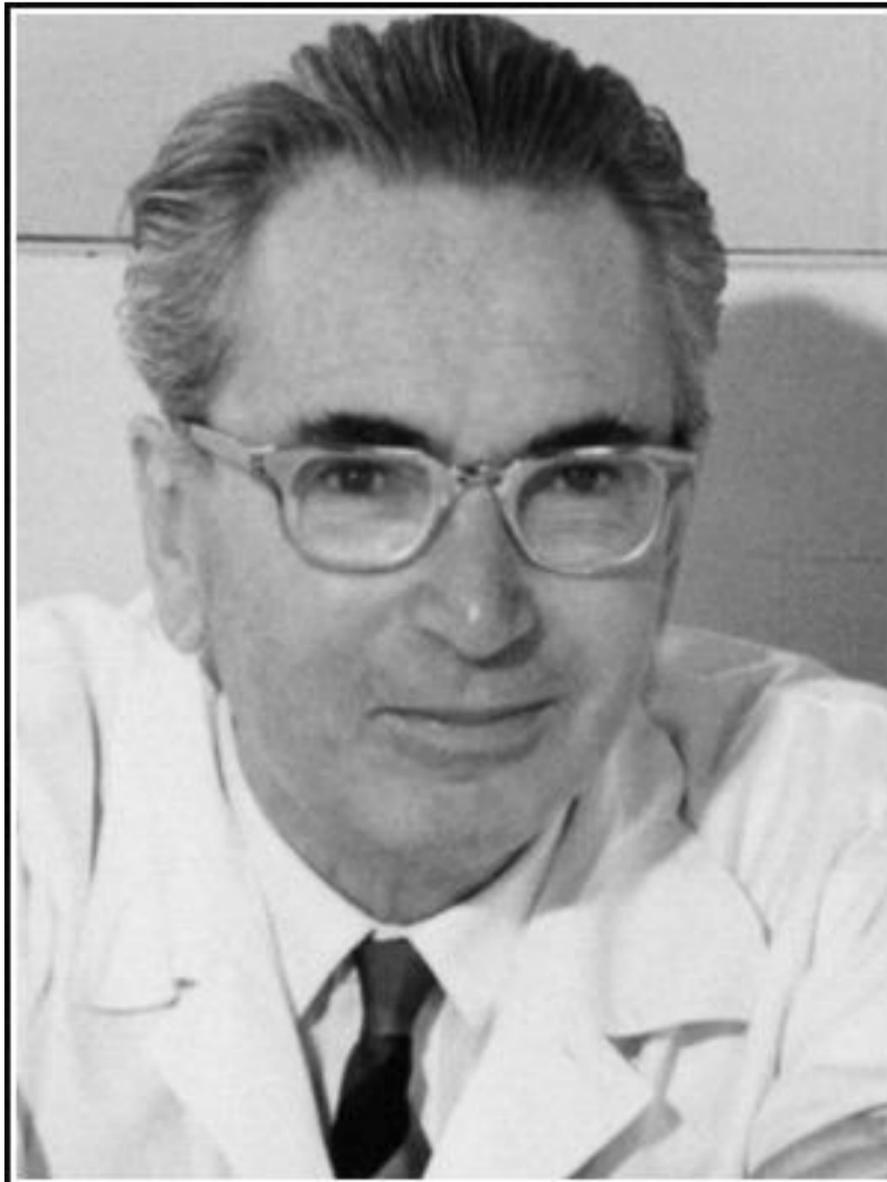
# At times it is education on self-care



Sheikh Ameena with colostomy.

Distressed and unable to do daily Namaaz due to the need to be ritually pure before starting to pray.

# At times it is meaning making



Logotherapy... considers man as a being whose main concern consists in fulfilling a meaning and in actualizing values, rather than in the mere gratification and satisfaction of drives and instincts.

— Viktor E. Frankl —

AZ QUOTES

# At times it is .....using common-sense

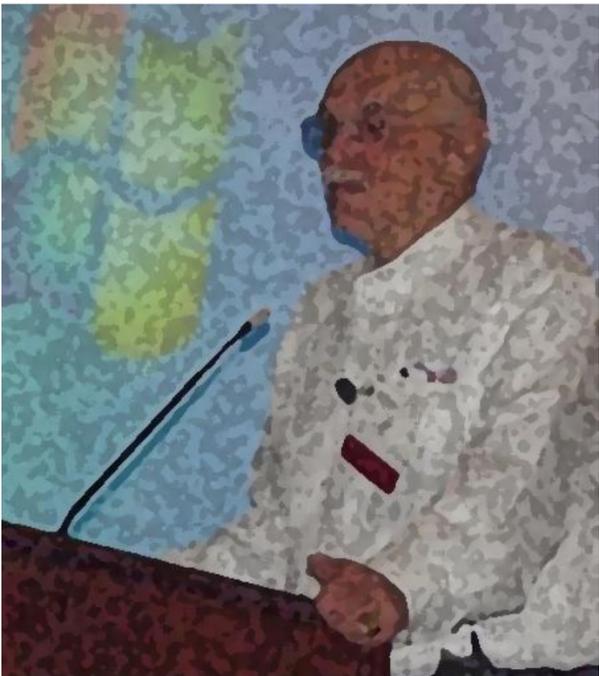
At times...Cognitive Behavioural  
Therapy – notice thoughts, feelings  
--> perceptions, experiences

At times it is psychotherapeutic interventions - surface-  
work” and “depth-work”:  
Art and music therapy, image work, dream work,  
mindfulness... meditation



At times it is enabling  
dignity - recall aspects of  
their lives that were most  
meaningful

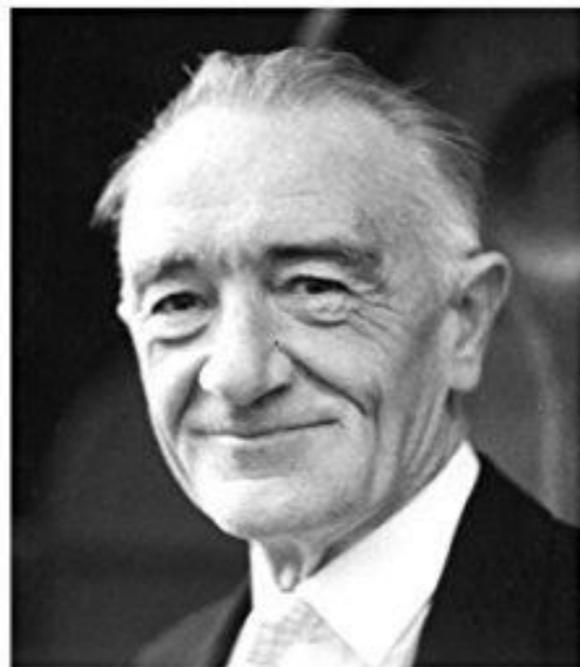
# OR.... help them find connections with their SGTO



# But mostly... it's being there for them...

## One Man's Medicine

An autobiography of  
Professor Archie Cochrane



Archibald L Cochrane with Max Blythe

### WW2 story of a sick Russian soldier

- *The ward was full, so I put him in my room as he was moribund and screaming as I did not want to wake the ward.*
- *I examined him. He had obvious gross bilateral cavitation and a severe pleural rub. I thought the latter was the cause of the pain and the screaming. I had no morphia, just aspirin, which had no effect.*
- *I felt desperate. I knew very little Russian then and there was no one in the ward who did. I finally instinctively sat down on the bed and took him in my arms, and the screaming stopped almost at once. He died peacefully in my arms a few hours later.*
- *It was not the pleurisy that caused the screaming but loneliness. It was a wonderful education about the care of the dying. I was ashamed of my misdiagnosis and kept the story secret.*

# Our Role as Healthcare Professional

- Compassionate Presence, Active, Genuine Empathetic listening
- Ask-Tell-Ask ..... invite discussions;
- NURSE .... (Are we engaging with spiritual fortitude)
- Explore spiritual concerns, non-judgemental, non-imposing
- Reverse the reversibles
- Appreciate the sharing, Should we talk about it again / later?
- **Align: Values, Principles, sense of dignity -> Quality of life**

## Take Home Message

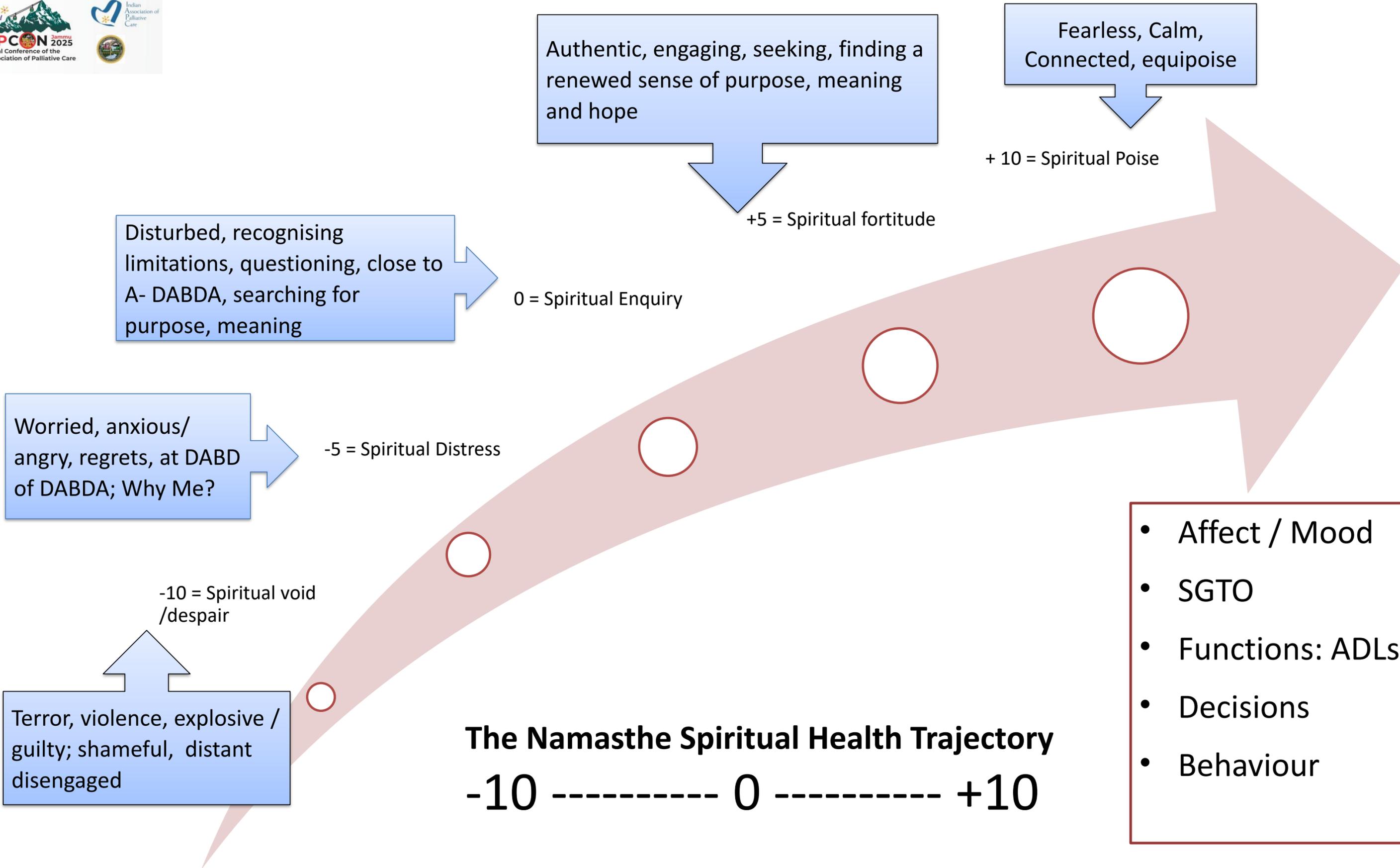
- Spiritual dimension is universal ... is at the core of our being
- Potentially this is where values are made, dignity developed, love and hope are felt
- It can express as seeking validation /connectedness...to the Absolute, the Great, the True, the Whole, the Perfect
- The pathway for seeking it .... are deeply personal **SGTO**
- Illness may erode and destroy, OR may reinforce the connectedness to the SGTO

## Take Home Message

- Spiritual leanings impacts healthcare-related-behaviour & decisions.
- 
- **“We ARE the Tool”**
  - Use CommSkills tool to Screen
  - Select and use appropriate Tools to assess
  - The framework approach using the Namasthe Spiritual Trajectory helps to comprehending the situation, navigate and monitor care
  - Provide contextual Car



**‘WE’ The Tool**



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



Thank you



# Practicing what not to do !

# Never-Words and Their Possible Alternatives

Never Words	Alternative Language	Rationale
There is nothing else we can do	“Therapy X has been ineffective in controlling the cancer, but we still have the chance to focus on treatments that will improve your symptoms and, hopefully your quality of life”	Even with no prospect for cure, the clinician can still convey an ability to treat the patient as best they can
She will not get better.”	“I’m worried she won’t get better”	Replace a firm negative prognostication with an expression of concern about the poor prognosis
“Withdrawing care”	“We can shift our focus to his comfort rather than persisting with the current treatment, which isn’t working.”	Clinicians never “withdraw” care, which may imply “giving up” or denial of services to patients and their families. Describe the advantage in refocusing the goal of care
“Circling the drain	“I’m worried she’s dying.”	Avoid slang terms that objectify and diminish patients

<p>“Do you want us to do everything?”</p>	<p>“Let’s discuss the available options if the situation gets worse.”</p>	<p>Instead of using a leading question that may not align with the patient’s values or goals, invite dialogue</p>
<p>“Everything will be fine.”</p>	<p>“I’m here to support you throughout this process.”</p>	<p>Offer support that is realistic and humane</p>
<p>“fight” or “battle</p>	<p>“We will face this difficult disease together.”</p>	<p>Avoid implying that sheer will can overcome illness. Patients may feel as if they’re letting their family down if they don’t recover (“if only she’d fought harder, she could have won”)</p>
<p>What would he want?”</p>	<p>“If he could hear all of this, what might he think?”</p>	<p>“Want” is often an ill-defined word in a hospital setting, and what families surmise the patient would want may be impossible</p>
<p>“I don’t know why you waited so long to come in.</p>	<p>“I’m glad you came in when you did.”</p>	<p>Blaming a patient and potentially causing more worry are unproductive. Focus on what can be done realistically in the given circumstances</p>
<p>“What were your other doctors doing/ thinking?”</p>	<p>“I’m glad you came to see me for a second opinion. Let’s look at your records and see where we can go next.”</p>	<p>Focus on what’s still possible. Take positive next steps, rather than casting aspersions on professionals whose cooperation you may still need in moving the patient forward</p>

# Herth Hope Index

Name: \_\_\_\_\_ Date: \_\_\_\_\_

The Herth Hope Index is a tool used to measure an individual's level of hope. Listed below are a number of statements. Read each statement and select the option that describes how much you agree with that statement right now.

	(1) Strongly disagree	(2) Disagree	(3) Agree	(4) Strongly agree
1. I have a positive outlook towards life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I have short and/or long range goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I feel all alone.*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I can see possibilities in the midst of difficulties.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I have a faith that gives me comfort.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I feel scared about my future.*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I can recall happy/joyful times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I have deep inner strength.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I am able to give and receive caring/love.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I have a sense of direction.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I believe that each day has potential.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I feel my life has value and worth.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Total score: \_\_\_\_\_

### Scoring

Scoring involves adding up points from each statement. Items 3 and 6 require reverse scoring. (These are marked by an asterisk\*). The maximum possible score on the full scale is 48, with higher scores indicating greater levels of hope.

Ref: Herth, P. (1992). Hope as a nursing construct: Renewing the spirit of care. Nursing Science Quarterly, 5, 129-135.

# The Purpose in Life Test (PIL)

(Crumbaugh & Maholick, 1964)

Write the number (1 to 5) next to each statement that is most true for you right now.

Items	Rate each item from 1 to 7	
1. I am usually:	bored	enthusiastic
	1 -----2-----3-----4-----5	
2. Life seems to me:	completely routine;	always exciting.
3. In life I have:	no goals or aims;	clear goals and aims.
4. My personal existence is:	utterly meaningless, without purpose	purposeful and meaningful.
5. Every day is:	exactly the same;	constantly new and different.
6. If I could choose, I would:	prefer to never have been born;	want 9 more lives just like this one.
7. After retiring, I would:	loaf completely the rest of my life	do some of the exciting things I've always wanted to
8. In achieving life goals I've:	made no progress whatever	progressed to complete fulfillment
9. My life is:	empty, filled only with despair	running over with exciting things
10. If I should die today, I'd feel that my life has been:	completely worthless	very worthwhile
11. In thinking of my life, I:	often wonder why I exist	always see reasons for being here
12. As I view the world in relation to my life, the world:	completely confuses me	fits meaningfully with my life
13. I am a:	very irresponsible person	very responsible person
14. Concerning freedom to choose, I believe humans are:	completely bound by limitations of heredity and environment	totally free to make all life choices
15. With regard to death, I am:	unprepared and frightened	prepared and unafraid
16. Regarding suicide, I have:	thought of it seriously as a way out	never given it a second thought
17. I regard my ability to find a purpose or mission in life as:	practically none	very great
18. My life is:	out of my hands and controlled by external factors	in my hands and I'm in control of it
19. Facing my daily tasks is:	a painful and boring experience	a source of pleasure and satisfaction
20. I have discovered:	no mission or purpose in life	a satisfying life purpose

**Scoring:** Add up all the scores for each item (20-100). A score of less than 50 may indicate that you are experiencing significant "existential concerns" in your life.\*

\* This instrument is only provided here as a way of exploring one's responses to these different existential questions. I am not in any way advocating for its clinical utility or its ability to provide any credible diagnostic value. Please be aware, for example, that the conceptual validity of this scale and some of its individual items has been questioned (e.g. high scores may be indicative of depression, not necessarily existential issues). In addition, there is significant cultural variability in responses – it may not be appropriate for culturally diverse populations. Please use it as a tool to 'think about' these issues and nothing more.

Ref: Crumbaugh, James. (1968). Cross-validation of Purpose in Life test based on Frankl's concepts. Journal of Individual Psychology, 24, 74-81.



## Self-Transcendence Scale

©Pamela Reed, PhD, RN, FAAN 1987



**DIRECTIONS:** Please indicate the extent to which each item below describes you. There are no right or wrong answers. I am interested in your frank opinion. As you respond to each item, think of how you see yourself at this time of your life. Circle the number that is the best response for you.

	Not at all	Very little	Some-what	Very much
<b><i>At this time of my life, I see myself as:</i></b>				
1. Having hobbies or interests I can enjoy.	1	2	3	4
2. Accepting myself as I grow older.	1	2	3	4
3. Being involved with other people or my community when possible.	1	2	3	4
4. Adjusting well to my present life situation.	1	2	3	4
5. Adjusting to changes in my physical abilities.	1	2	3	4
6. Sharing my wisdom or experience with others.	1	2	3	4
7. Finding meaning in my past experiences.	1	2	3	4
8. Helping others in some way.	1	2	3	4
9. Having an ongoing interest in learning.	1	2	3	4
10. Able to move beyond some things that once seemed so important.	1	2	3	4
11. Accepting death as a part of life.	1	2	3	4
12. Finding meaning in my spiritual beliefs.	1	2	3	4
13. Letting others help me when I may need it.	1	2	3	4
14. Enjoying my pace of life.	1	2	3	4
15. Letting go of past regrets.	1	2	3	4

Possible scores: 15 to 60

Higher scores → greater self-transcendence.

Generally, 15 to 30 = low level of self-transcendence;

31-45 is moderate;

and 46 to 60 is considered high levels of self-transcendence

Ref: Reed, P.G (2015). Pamela Reed's Theory of Self-Transcendence. In M.C.Smith & M.E. Parker (Eds.). Nursing theories & nursing practice (4th ed.) (pp. 411-420). Philadelphia: F.A. Davis.

***Thank you very much for completing these questions. On the back of this sheet, please write down any additional comments that may help us understand your views.***



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Thank you ,and Namasthe