



# 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.

## How do we provide Spiritual Care? Demonstration and Exercises



# Learning to screen for Spiritual Distress



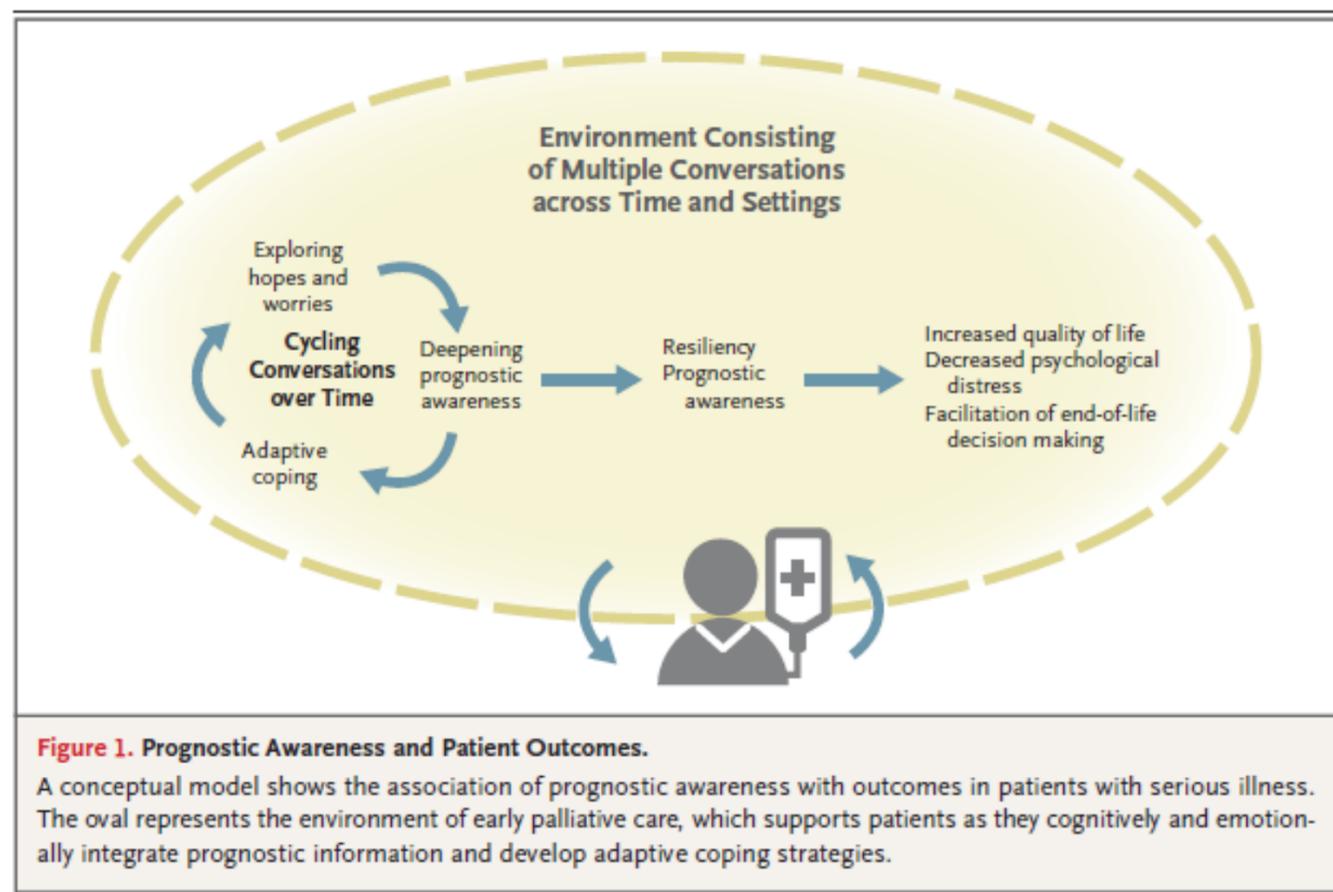
# Case Study

# Bhavna in the OPD

**1** This is the story of Bhavna whom we first met in the last quarter of 2021. She was 26 years old, a lecturer in an IT college and looking forward to a future of working and supporting her mother who had raised her. She had lost her father two years ago. Her brother and sister were pursuing their graduation. She had been diagnosed with spindle cell sarcoma of the right maxilla, operated two months ago and then planned for adjuvant therapy. She was referred to us in palliative medicine for pain control. She was apprehensive, hopeful that treatment would rid her of disease and regular with treatment. did not miss any follow ups and diligently pursued treatment. It was a blow to her that she could no longer go to college and teach and she was trying to adjust to this new normal.

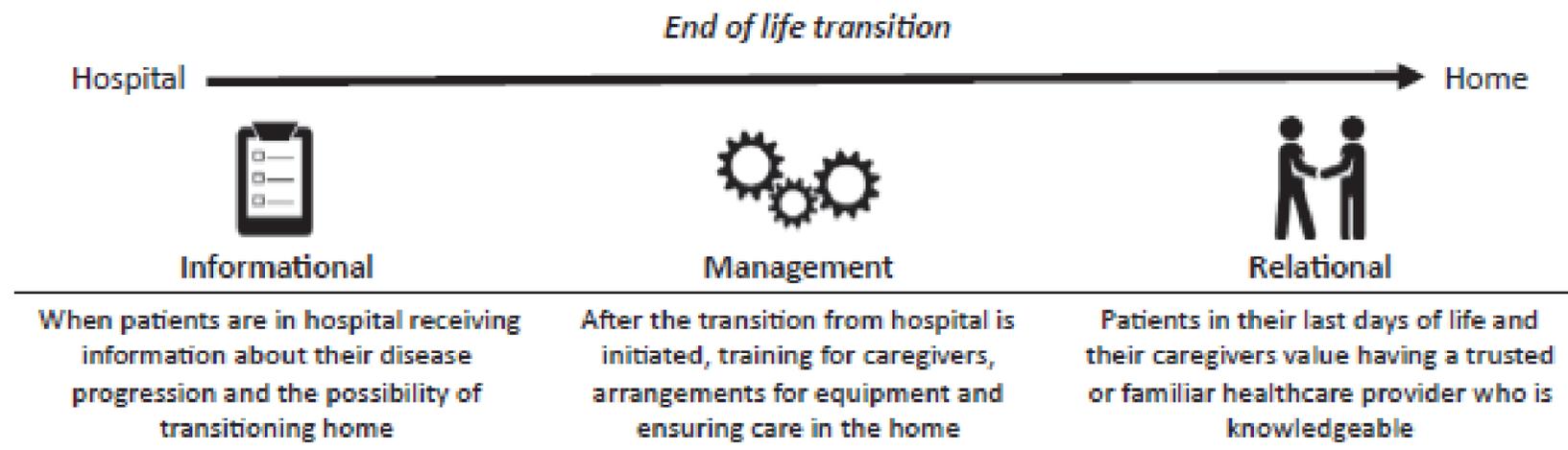
- In early 2023, she developed orbital swelling. This was followed by discharge from the tumour and she presented with bouts of epistaxis and hematemesis. Her disease had recurred, the goals were now palliative and she was planned for radiation and chemotherapy.

- She was following up with psycho oncology as she had self-image issues. She was reviewing with our speech and swallow therapist along with the Head and Neck and Med Oncology team. She was on regular follow up with our department for her pain and symptoms. She would insist on T Tapentadol and avoid T Morphine. We preferred to give her Morphine for medical reasons but she would resist. She was very diligent with her schedule in spite of the distance she had to travel for treatment. She tried her best to stay well groomed and carried her own set of tissues to dab her eye and clean her secretions when needed. She managed her odour and wound dressing well. She had a gentle demeanour and now had a nasal twang in her voice post the disease. She articulated well and loved to describe and talk to us.



Bhavna as a person

Jackson VA, Emanuel L. Navigating and communicating about serious illness and end of life. *New England Journal of Medicine*. 2024 Jan 4;390(1):63-9.



Morey T, Scott M, Saunders S, Varenbut J, Howard M, Tanuseputro P, Webber C, Killackey T, Wentlandt K, Zimmermann C, Bernstein M. Transitioning from hospital to palliative care at home: patient and caregiver perceptions of continuity of care. *Journal of pain and symptom management*. 2021 Aug 1;62(2):233-41.

Fig. 2. Types of continuity and the time period in a transition, where each type is particularly important.

# Bhavna in the OPD

- One afternoon, a year after her recurrence, she was wheeled into the OPD by her mother. She had been in the wheel chair the past few consults but today, there was a difference. Her usual greeting was absent and her head was bowed down. As I moved my chair closer to hers, she said, "I was taking treatment, but now when they said you need not come to the hospital, I was so sad and cried a lot."<sup>2</sup>
- <sup>3</sup>Moving my chair towards her and reaching out to her, I said softly, "Bhavna, I can see how sad you are" Pause, silence <sup>4</sup>
- "I am constantly able to hear an inner voice telling me 'Bhavna, your time is finished now. I prefer to sleep for most of the time so that I don't have to listen to this inner voice and I can feel no pain while I am in sleep. As soon as I wake up, my pain starts, which is unable to bear.'"<sup>5</sup>

# Distress Screening

- Non Verbal cues
  - Verbal Cues
  - Tools ?
- 
- Is there spiritual distress ? Why ?
  - What would you like to address first ?

# Bhavna in the OPD

- 6 I am so sorry Bhavna, this is a very difficult time, but please remember that just because we are stopping chemotherapy, it does not mean that the worst will happen immediately. We are not stopping all medications. **Pause-** We will continue to give you all the medicines to bring down your symptoms like pain, smell, bleeding. We will be in touch with you regularly. **Pause-** If you feel like visiting us, you are most welcome, you can also video call..  
**.....pause , silence –**
- 7 Are you taking the pain medications? You mentioned now that you wake up with pain, how are you taking them?
- 8 "My mother gives me the medication all the time; **mom will never allow me to eat medicines on my own as she fears I may eat more tablets at once.**"
- 9 Did you ever feel like having more meds at once?" tone and posture

# Bhavna in the OPD

•10 "No mam, I am a Christian; till my time is there on this Earth, I have to bear this suffering. If I do something like suicide, I fear that I may go to hell. So, I will bear all this pain while I am on Earth, and when my time is over, I will go to heaven."

•That is a lot of faith. Does this faith help you ?

•11 "But I know that I am stronger, and since I am bearing all this treatment till now, I still have faith that I may become fine."

•12 It is good to have faith and all of us will be grateful for a miracle. But in case it does not, we need to be prepared, right? Pause

•And our medicines make you feel better so that you can engage in what you like ..like reading . So, please take the extra medications when you have pain

# Tools for screening distress

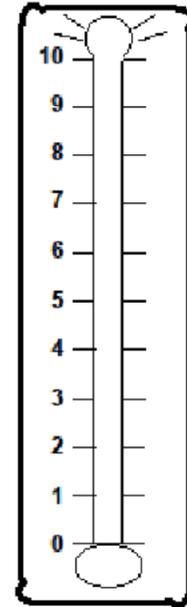
- HCW is the tool
- Addressing the physical component
- Ask Tell Ask
- NURSE Tool
  - **Name:** Greet the patient by name
  - **Understand:** Try to understand the patient's emotions
  - **Respect:** Treat the patient with respect
  - **Support:** Provide support to the patient
  - **Explore:** Explore the patient's emotions further
- In the trajectory , where is her distress level ?

**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

Note: All recommendations are category 2A unless otherwise indicated.

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**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
- Prejudice or discrimination

**Practical Concerns**

- Taking care of myself
- Taking care of others
- Safety
- Work
- School
- Housing/Utilities
- 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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\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

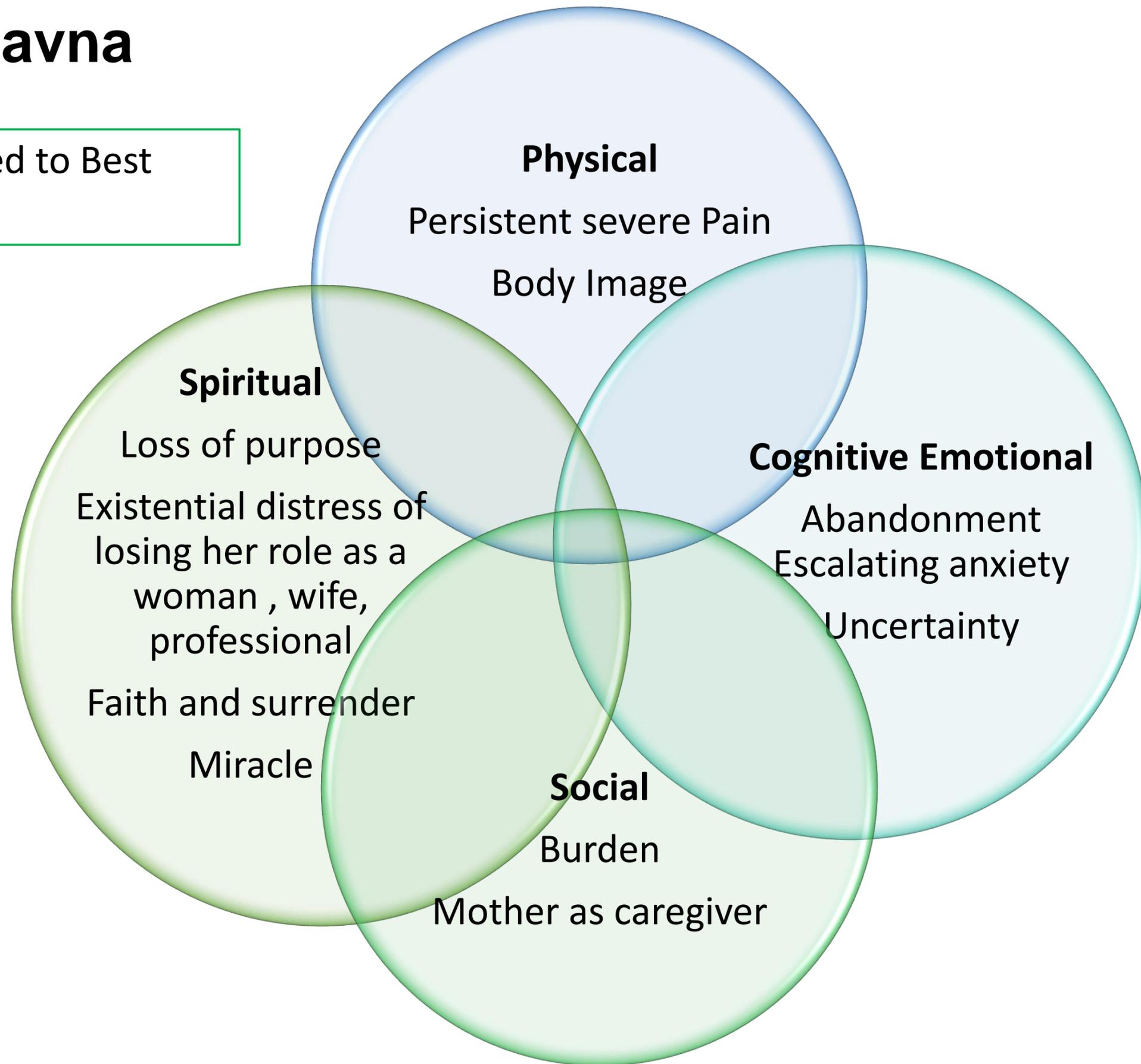
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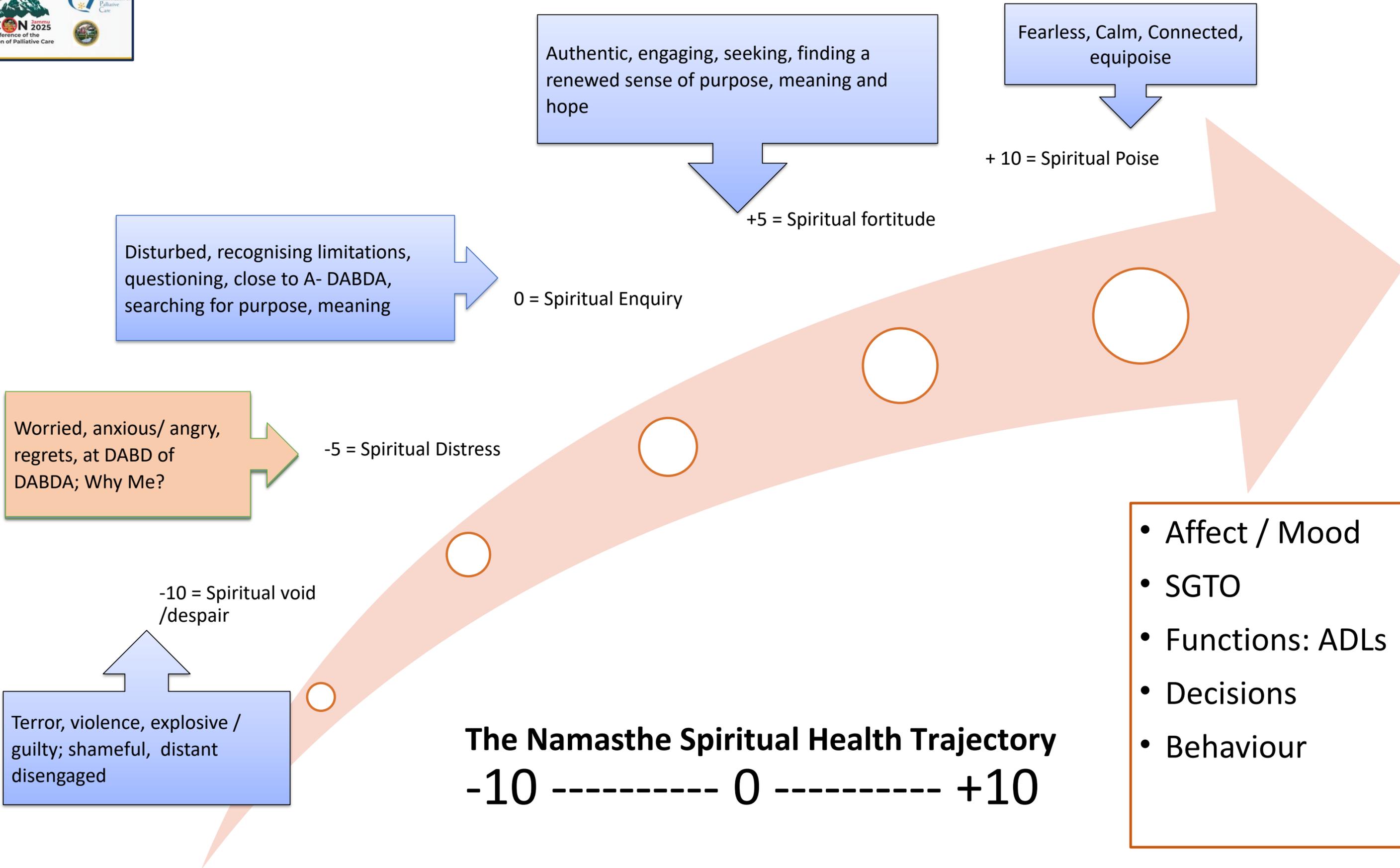
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DIS-A

# Bhavna

As she transitioned to Best Supportive Care





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



FICA Tool	
<b>F – Faith, Belief, Meaning</b>	<p><b>Religious/Religiosity</b> – Pertains to one’s beliefs, behaviors, values, rules for conduct, and rituals associated with a specific religious tradition or denomination (O’Brien, 1999).</p> <p><b>Spirituality</b> – Generally, an “individual’s attitude and beliefs related to transcendence (God) or to the nonmaterial forces of life and of nature...the dimension of a person that is concerned with ultimate ends and values” and meaning (O’Brien, 1982, p. 88; Taylor, 2006).</p>
<ul style="list-style-type: none"> <li>Do you consider yourself spiritual or religious?</li> </ul>	
<ul style="list-style-type: none"> <li>Do you have spiritual beliefs that help you cope with stress?</li> </ul>	
<ul style="list-style-type: none"> <li>What gives your life meaning?</li> </ul>	
<b>I – Importance and Influence</b>	
<ul style="list-style-type: none"> <li>What importance does your faith or belief have in your life?</li> </ul>	
<ul style="list-style-type: none"> <li>On a scale of 0 (not important) to 5 (very important), how would you rate the importance of faith/belief in your life?</li> </ul>	
<ul style="list-style-type: none"> <li>Have your beliefs influenced you in how you handle stress?</li> </ul>	
<ul style="list-style-type: none"> <li>What role do your beliefs play in your health care decision making?</li> </ul>	
<b>C – Community</b>	
<ul style="list-style-type: none"> <li>Are you a part of a spiritual or religious community?</li> </ul>	
<ul style="list-style-type: none"> <li>Is this of support to you and how?</li> </ul>	
<ul style="list-style-type: none"> <li>Is there a group of people you really love or who are important to you?</li> </ul>	
<b>A – Address in Care</b>	<p>We have talked a lot about your spirituality and/or religious beliefs and how they may or may not be of help to you during your illness. How can your health care providers best support your spirituality?</p>
<ul style="list-style-type: none"> <li>How would you like your health care provider to use this information about your spirituality as they care for you?</li> </ul>	

Fig. 1. FICA Tool.

Borneman T, Ferrell B, Puchalski CM. Evaluation of the FICA tool for spiritual assessment. Journal of pain and symptom management. 2010 Aug 1;40(2):163-73.

TABLE 4  
Examples of Questions for the HOPE Approach to Spiritual Assessment

**H:** Sources of hope, meaning, comfort, strength, peace, love and connection  
 We have been discussing your support systems. I was wondering, what is there in your life that gives you internal support?  
 What are your sources of hope, strength, comfort and peace?  
 What do you hold on to during difficult times?  
 What sustains you and keeps you going?  
 For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life’s ups and downs; is this true for you?  
 If the answer is “Yes,” go on to O and P questions.  
 If the answer is “No,” consider asking: Was it ever? If the answer is “Yes,” ask: What changed?

**O:** Organized religion  
 Do you consider yourself part of an organized religion?  
 How important is this to you?  
 What aspects of your religion are helpful and not so helpful to you?  
 Are you part of a religious or spiritual community? Does it help you? How?

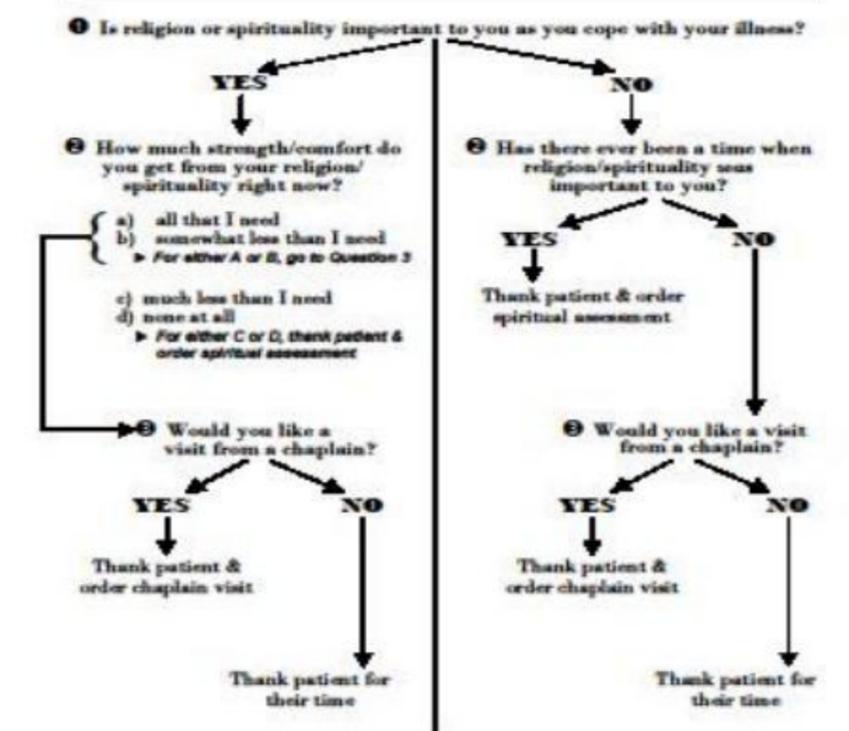
**P:** Personal spirituality/practices  
 Do you have personal spiritual beliefs that are independent of organized religion? What are they?  
 Do you believe in God? What kind of relationship do you have with God?  
 What aspects of your spirituality or spiritual practices do you find most helpful to you personally? (e.g., prayer, meditation, reading scripture, attending religious services, listening to music, hiking, communing with nature)

**E:** Effects on medical care and end-of-life issues  
 Has being sick (or your current situation) affected your ability to do the things that usually help you spiritually? (Or affected your relationship with God?)  
 As a doctor, is there anything that I can do to help you access the resources that usually help you?  
 Are you worried about any conflicts between your beliefs and your medical situation/care/decisions?  
 Would it be helpful for you to speak to a clinical chaplain/community spiritual leader?  
 Are there any specific practices or restrictions I should know about in providing your medical care? (e.g., dietary restrictions, use of blood products)

*If the patient is dying:* How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. American family physician. 2001 Jan 1;63(1):81-9.

**Religious Struggle Screening Protocol**



Fitchett G, Risk JL. Screening for spiritual struggle. Journal of Pastoral Care & Counseling. 2009 Mar;63(1-2):1-2.

# AMEN

- Affirm the patient's belief. Validate his or her position: "Ms X, I am hopeful, too."
- Meet the patient or family member where they are: "I join you in hoping (or praying) for a miracle."
- Educate from your role as a medical provider: "And I want to speak to you about some medical issues."
- No matter what; assure the patient and family you are committed to them: "No matter what happens, I will be with you every step of the way."

The heart of the AMEN protocol is the commitment to joining rather than placing more distance between patient and provider. The "and" aligns rather than distances and possibly opens dialogue by allowing the physician to say, "It is God's role to bring the miracle, and it is my role as your physician (or nurse) to bring you some important information that may help us in our decision making." Hope becomes the common ground for provider and patient or family as all parties concerned reason together for the best care possible.

Cooper RS, Ferguson A, Bodurtha JN, Smith TJ.  
AMEN in challenging conversations: bridging the gaps between faith, hope,  
and medicine.

Journal of Oncology Practice. 2014 Jul;10(4):e191-5.

- **13** Yes, this medication is 3 or 4 times more effective and important when compared to chemotherapy and radiation. 'Reading, I feel tired now, can't help my mother also. "I feel bad that my mother stopped doing the marriage bureau business since a year as I am not well. "
- "Sometimes, I feel bad when I see all my friends getting married and having kids... but all my friends are in contact with me, and they frequently come to visit me every weekend or during holidays."
- **Acknowledge, non-verbally**
- "Today, I saw a patient in front of the chemo OPD; he was an old uncle, same like me but for him, removal of the eye was done, and he has disease spread to hip region. Then I felt at least I didn't get any removal of eye ball or no spread to the other side for that I felt so contented."
- "There are still many people who don't know that HBCHRC exists here in Vizag, and many patients are not getting treatments. I am feeling bad for that."

# Tool

- What was happening ?
- Tool used by the HCP
  
- Active Listening
- Silence

# Bhavna in the OPD

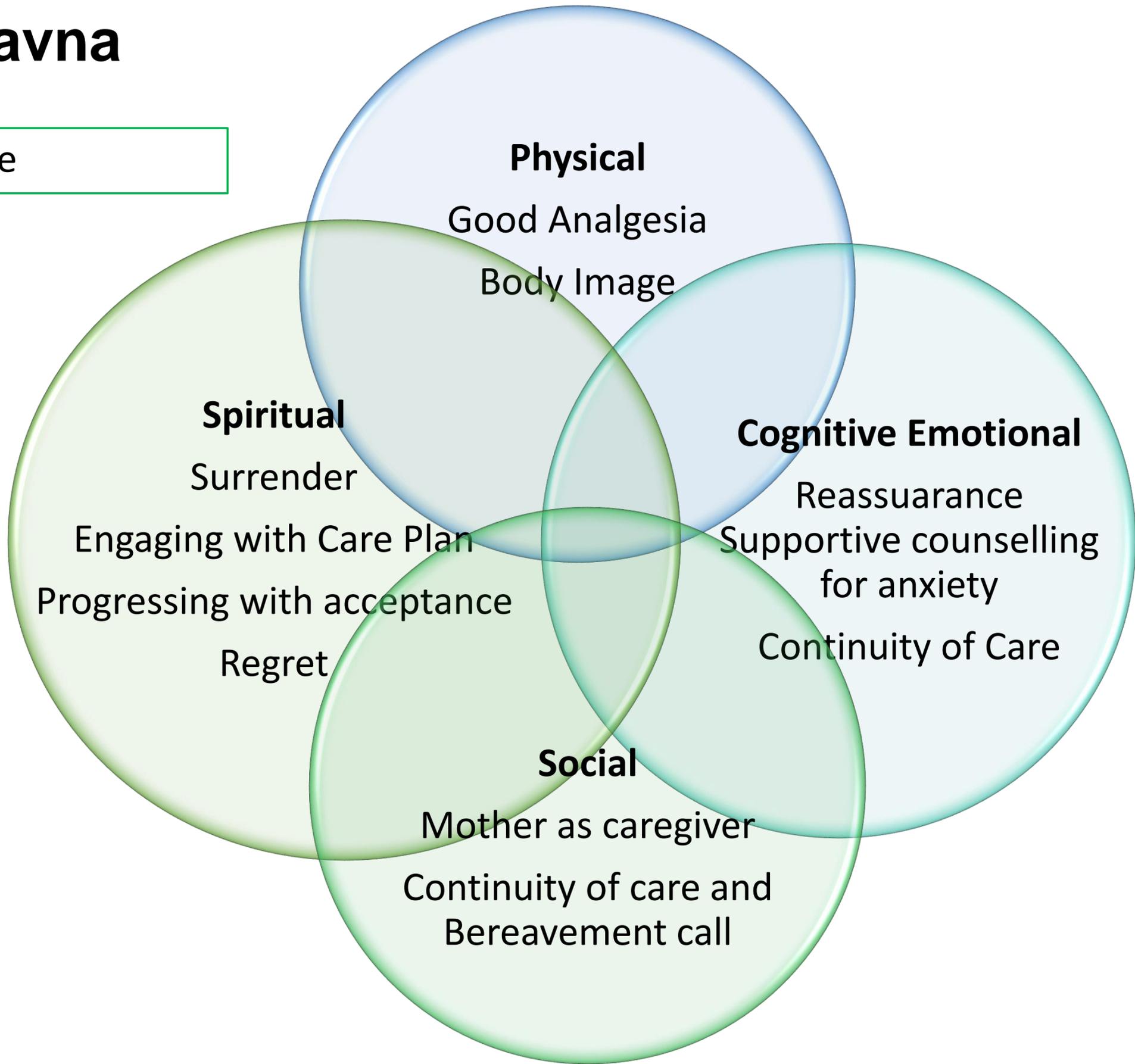
- 14 In the midst of what you are going through, you have the ability of thinking of the troubles that others are facing, that is so admirable
- "Mam, I feel so happy and relieved after talking with you. Thank you for encouraging me and giving me courage. "
- 15 I wish we could do more, it is sad for us too
- 16 "Why mam, let's leave sadness and let me be happy only."

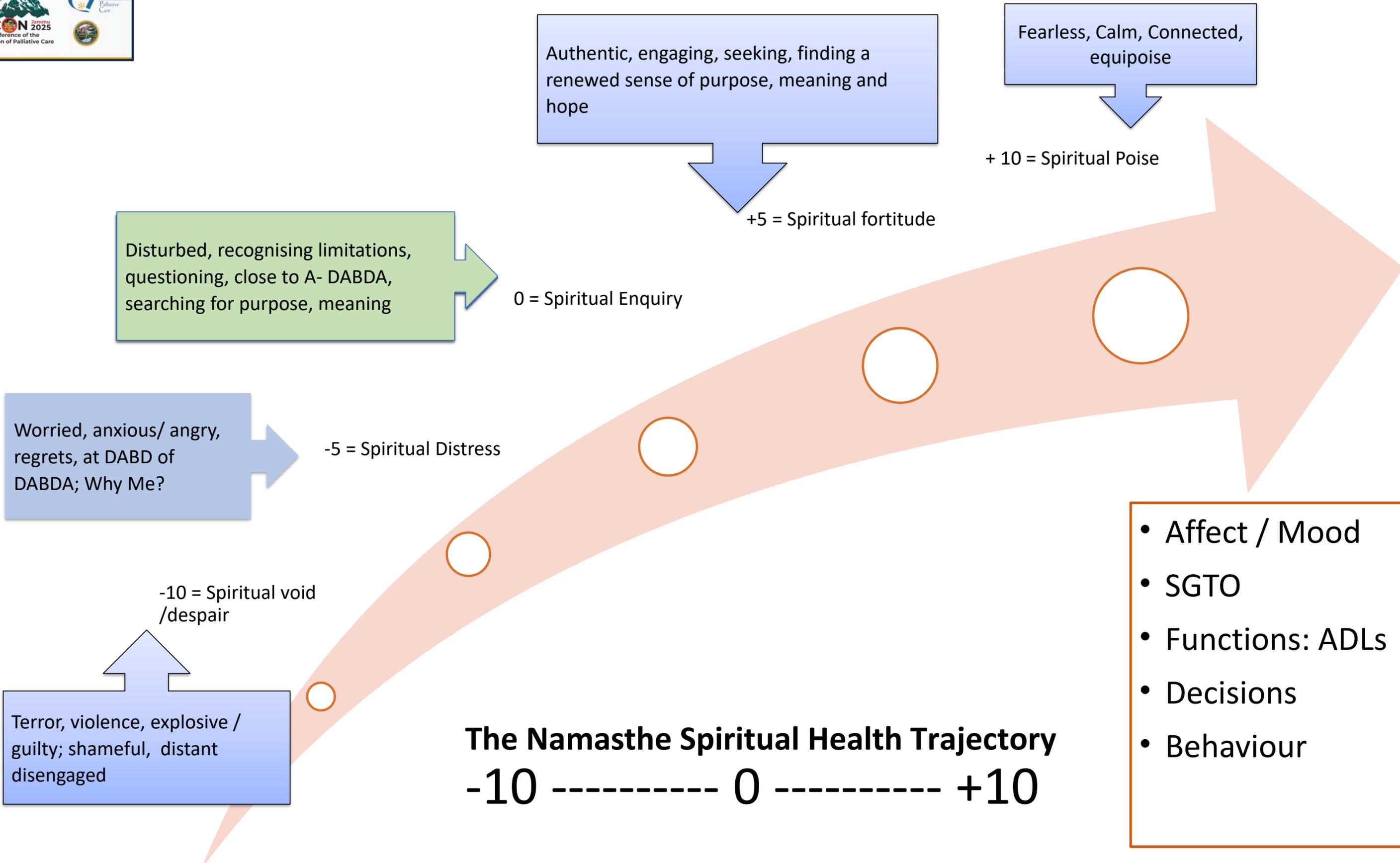
# What happened after ?

- Bhavna lived far away and we followed up through video calls and telephone calls . We could convince her to take medication and we thought she was more comfortable
- One day , she travelled all the way and visited the OPD. She met all her doctors, her symptoms were getting worse. She remained at a scale of 0, reflective and brewing sometimes .
- She gradually declined and died in her home about two weeks later

# Bhavna

Towards End of Life





Worried, anxious/ angry, regrets, at DABD of DABDA; Why Me?

-5 = Spiritual Distress

Disturbed, recognising limitations, questioning, close to A- DABDA, searching for purpose, meaning

0 = Spiritual Enquiry

Authentic, engaging, seeking, finding a renewed sense of purpose, meaning and hope

+5 = Spiritual fortitude

Fearless, Calm, Connected, equipoise

+ 10 = Spiritual Poise

Terror, violence, explosive / guilty; shameful, distant disengaged

-10 = Spiritual void /despair

**The Namaste Spiritual Health Trajectory**  
-10 ----- 0 ----- +10

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



Approach to managing Spiritual Suffering



# Case Study



# A daughter's distress

How would you respond?

# A daughter's distress

The daughters of the patient were her caregivers .Patient Mrs Munira was 49, admitted in the ward and now planned for Best Supportive Care . Her husband had deserted her a year ago. Both the daughters had married but it had not worked out . There was minimal family support from the uncles . Our resident doctors were finding it very difficult to counsel the daughters as they kept asking for scans and further reports

Attributes	Spiritual Distress
Affect	Very sad , anxious , wishes for scans and reports and wonders what can be done next Conflicted – says she understands the prognosis and wishes for the scans and reports too Overwhelming sense of loss and need for reconciliation and acceptance Unable to accept , fear about the future Spiritual Distress -5
SGTO	Feels everything has failed her and she has failed her mother
Functions	Managing CG duties with her sister
Behaviour	Distressed , crying , fearful and anxious
Decisions	Ambiguous , Able to make decisions but needs help

I have failed , isn't it ?

Silence ..Why do you feel that way ?..What was your duty ?

To bring her to the hospital

Did you do that ?

Yes

Then how did you fail ?

No answer , thinking

It is the disease we have no control over ...

**I want to go away with  
my mother**

Silence – can only imagine how sad you are .. You just told me how much your mother did for you .. You spoke about the way she looked after you two, even washed and ironed your clothes ..silence  
Then, how would she feel if she heard this ?  
Is this what she would have wanted for you ?...

**I went to every temple and prayed ,  
went to a church , did so much .  
Every thing is false , isn't it ? There is  
no truth in all this**

I am sorry , you must be hurting so much . Do you think each of what you did gave you the strength to come this far ? Pause

Everytime you did something or prayed , you went one step ahead in looking after your mother ? ...So, maybe it gave gave you strength from inside? Pause

Nodding in affirmation

Because both of you girls have done so much with so little family support

Is it fair that both our parents are leaving us at the same time ? How is it correct ?  
How are we going to manage?

And like you said, it is not right .(Pause)

Can we take one step at a time? We are going to keep your mother comfortable . And we can wait for the 1<sup>st</sup> and see if your father calls . Otherwise we can help talk to your uncle, isn't it ? Wait for response

Thinking

Your mother has raised you two so well, you'll are so responsible . Would you be able to talk to your mother at home about what you would like to do or plan ?

Nodding in affirmation sadly

There is no hope at all , it has gone

Pause...you have brought her so far with hope , even now we are going to hope for her to be comfortable, for her symptoms to be under control , hope for her to be able to talk with you two for as long as possible.....

Yes ...and who is her hope?

Replies --- we . So please repeat ..that we are her hope ...



# Case Study

# The story of K and K

Kanamma and Kanappa were the names we gave this couple whom we met when Kanappa was admitted to the ICU. Kanamma was 60 years old, and Kanappa was 72 years old. They had been married for 40 years and did not have children. They were always each other's support, living a life of simplicity and deep mutual care. Despite the challenges of aging and illness, their unwavering bond was evident in the way Kanamma cared for Kanappa, staying by his side and ensuring his comfort throughout his time in the ICU.

Kannamma walked into the outpatient department (OPD) in a hurry. She had come to learn about palliative care after the ICU doctors told her about us, while her husband, Kannappa, remained in the ICU. Kannamma was looking around checking the name boards and walked into the OPD with her eyebrows raised, clutching a small notebook and a pen. She looked around and as she sat down, she began asking a series of questions in quick succession.

"What will palliative care do? How can you help us?" she asked repeatedly.

I paused for some time, looking blank and asked her, "What happened?"

"My Husband is in ICU, doctors told he is not responding to anything, and I don't have much money or anyone to help me, So Dr M asked me to come to you all in the palliative department"

"Okay... I smiled, My name is Ann, I am working as a psychologist here, what is your name and could you tell me a little more about what happened to your husband?"

"Sighing, "My husband had a stroke. This is the second stroke, he might not come out of this... Trembling"

"Sorry, that is difficult, do you want some water?"

"I have no time, as my husband is alone there so can you tell me what palliative care is and what you would do"

I patiently explained what palliative care is, and how we can provide comfort for her and her husband.

She noted all the points and before leaving "Ok ok, I understood now, but I want to think for some more time, but thank you, I forgot your name, what was it"?

"No problem, we shall also discuss it with our team and ICU doctors and, I am A, smiling"

She nodded, got up and left in a hurry.

## Next Day In ICU

"Good morning, Kannamma. We spoke to the ICU doctors and wanted to check in and see how you and Kannappa are doing today."

"I'm trying, but there's so much on my mind. If Kannappa moves out of the ICU... (Trembling with her eyes popped out) will there be nurses with him all the time? What if something happens? Who will help me?"

"Nodding..with a touch on her shoulder ..We can understand your concerns, Kannamma. It's completely normal to feel overwhelmed right now. But yes, there will be nurses available 24/7, and you will always have someone to reach out to if you need help. You're not alone in this."

"But it's all so uncertain. I'm scared... scared of not being able to manage everything, I dont have anyone, nobody to help."

"Hmm Let's sit and have this conversation in the counselling room, The team involved three doctors Dr N and the junior residents who sat in a U along with Kannamma "We'll be right here to guide you through each step. Kannappa's care is still our priority, even after he leaves the ICU. Let's take it one step at a time, together."

*(As the conversation continued, Kannamma gave a faint smile, began to soften.)*

"Sighing ...Thank you...."

"Absolutely. You're doing an incredible job being there for Kannappa, and we'll make sure you feel supported too."

Both the parties got up and walked out of the room after greeting each other

*(After the conversation, the team regrouped to discuss the plan with the ICU team.)*

**ICU Doctor:** "There's something we need to address before moving forward. Kannamma has expressed suicidal thoughts."

"Oh... Okay...with a surprise on Dr N's Face, Thank you for sharing this We will Ask our psychiatrist and psychologist to come and talk to her"

**Dr P who is the Psychiatrist along with A and The MSW arranged a meeting with Kannamma**

"Good evening, Kannamma. We're here to check in on you and offer support. I am Dr P, This Is A whom you have already met and this is our MSW N, "How are you feeling right now?"

"With a smile.. Yes yes I know A and N, I met them.. Ahh ..I don't know... Why are all of you here anyways? I'm fine."

"We're here to talk to you and check on you. We've noticed how much you've been carrying, and we want to make sure you're not doing it alone. It's okay to talk to us."

"Hesitantly, with a raised eyebrow, turning her face away..raising her hand she said "What's the point? No one can change anything. I can't live without him. I just... I want to die with him."

"That's a lot of pain to carry, Kannamma. You love Kannappa deeply—it's clear how much he means to you. It's okay to feel overwhelmed, but you don't have to face this alone."

"You don't understand. He's my world. Without him, what's left for me?"

"We hear you, Kannamma. It's clear how much you care about him, and it's also okay to feel scared and uncertain. And it is during these times people feel like hurting themselves, do you feel that way?"

"What..... No No... Jesus has already decided our time. Everything is in His hands."

"Your faith seems very important to you, Kannamma. It's something that's helping you hold on right now. Can you tell us more about what gives you strength in your faith?"

"I believe He knows what's best..... I've been let down so many times before. By people. How can I trust anyone again? Only God I trust

"Would you like to talk about it"??

"No.... with her eyebrows raised... Why do you want to know that??"

"We just want to check on you, Make sure you are okay and let you know that we are here for you."

Kannamma let out a heavy sigh and said, "I just want to focus on helping my husband feel better." She hesitated for a moment before adding, "I'm not comfortable talking about my personal life." With a polite but firm tone, she thanked us and quietly left the room.

After Kannappa's transfer from the ICU, Kannamma needed time and counseling to adjust to palliative care. And, she also struggled to retain caregivers due to her high expectations.

"Kannamma, how are things after Kannappa's shift to palliative care?"

"It's hard.. (With frustration) Caretakers don't meet my standards, and they leave. I just want the best for him."

"We see how much you care. Let's work on finding someone who understands your needs and help make this easier for you."

\*(One day, after Kannappa's blood pressure dropped...)

**(Agitated)** "Why aren't you taking proper care of him? This shouldn't have happened..(Rubbing his hand)!"

"We understand your worry. Let's address this and ensure you feel confident in his care moving forward."

(Kannamma was overwhelmed at this point of time, we sat down and spoke, eventually she made sense of what was happening around her. Kannamma bonded with a new caretaker, easing her stress. As she prepared to bring Kannappa home...)

*As we begin to speak regarding discharge...*

"I'm worried my house isn't ready for his care needs and how will I care for him alone?."

"Patting her back.... Stay assured, we will provide you with homecare and will also provide you with the contact number for Sahaya so you can arrange everything Kannappa needs at home. "

“Okay... I shall contact Sahaya today itself”

With the necessary arrangements in place, Kannappa was smoothly transitioned to their home, where Kannamma could provide him with the care and love she deeply desired. Surrounded by the comforts of home and his wife’s unwavering attention, Kannappa took his last breath one week after discharge.

## Discussion Points

Could you place Mrs Kannama on the spiritual distress trajectory ?

What are the various domains of distress ?

What did you notice about Ann which facilitated the start of the conversation?

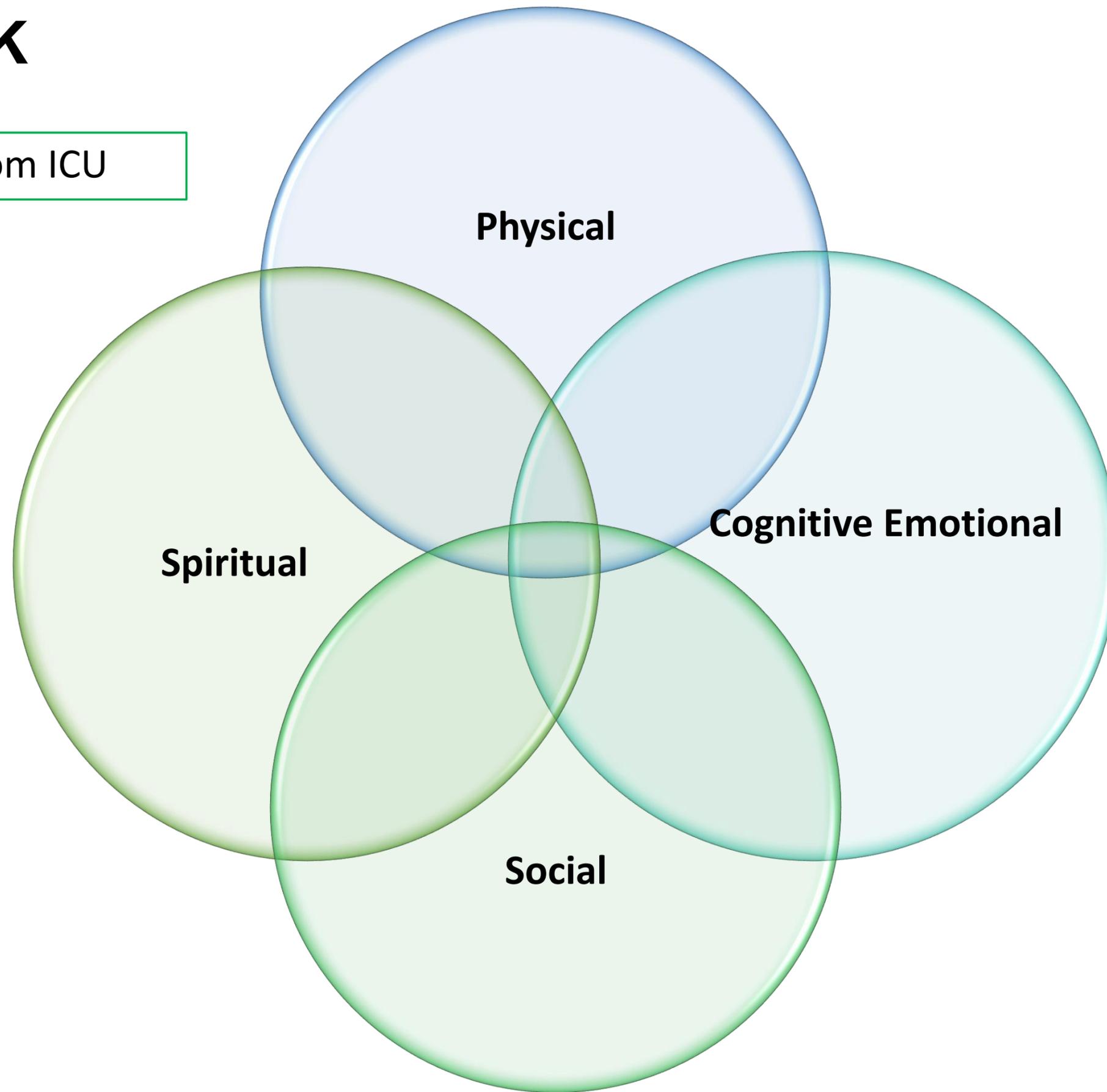
What were the communication tools used here?

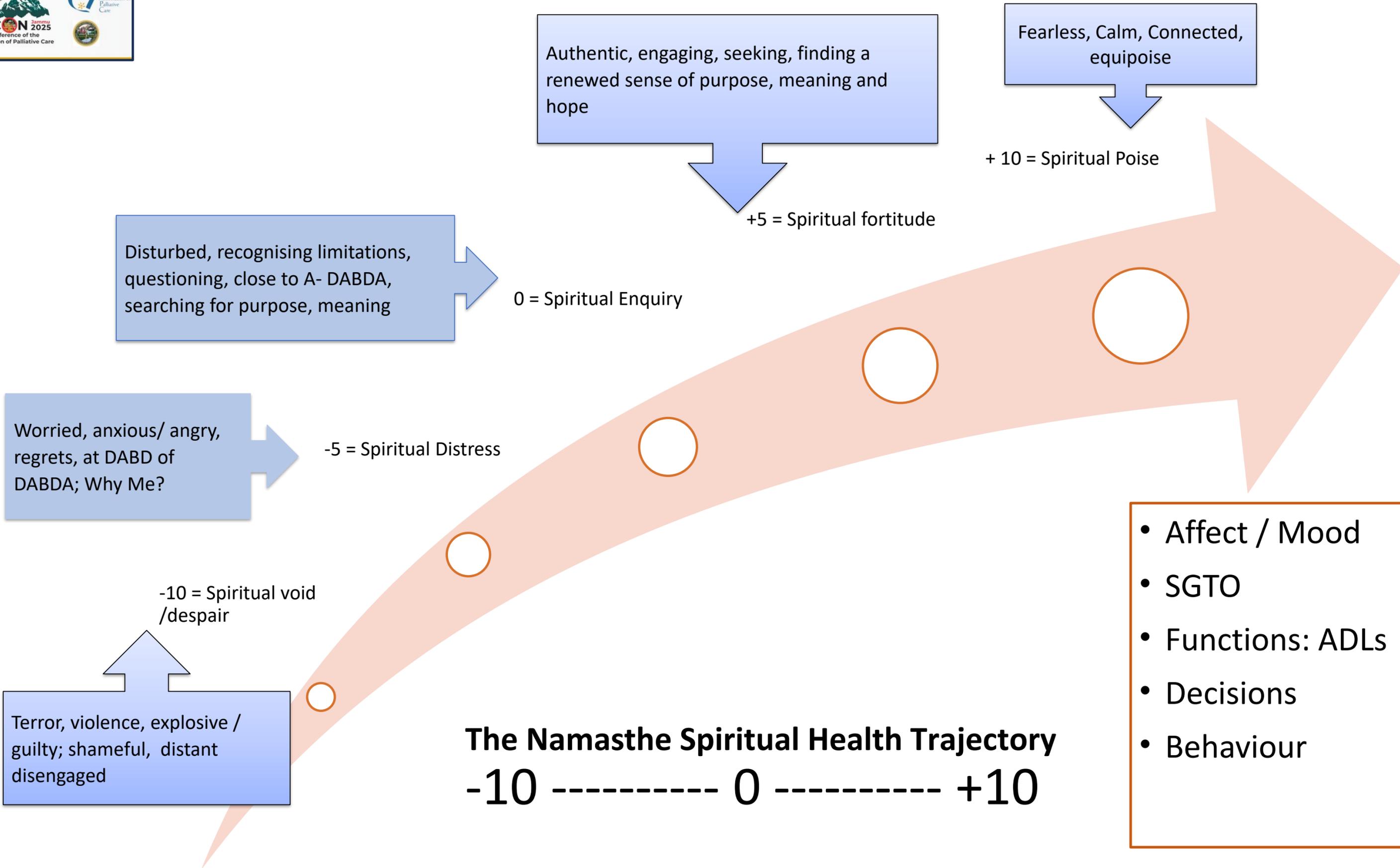
Could you translate Ann's responses in your local language?

How would you have done this differently?

# Mrs K

Transition of Mr K from ICU





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



**Approach to  
managing Spiritual  
Suffering**

# Manoj's Story

We, in the palliative medicine department received a referral for Mr Manoj , a 66-year-old man diagnosed with skeletal metastases of an unknown primary origin. As we climbed to the fourth floor, his cries of pain echoed through the corridors. On arrival, we found Mr. Manoj in significant distress, struggling with intense pain. With due diligence, we promptly prescribed and administered medication to alleviate his discomfort. Over time, the treatment began to take effect, and his pain subsided noticeably.

After some time, Dr. N checked on Mr. Manoj. As she came in, she noticed his wife next to him. They were quietly talking. As soon as Mr Manoj saw Dr N , he grimaced and said, “My pain has come back...my back hurts so badly..”

Dr N sat beside him and said gently, “I can see the pain is coming back. Can you tell me more?”

“Ahh.. (swallowing his saliva)... It's not as bad as before, but it's there,” he said, shifting uncomfortably. “What if it gets worse at home? What will I do then?”

“We'll adjust your medications.. ..Let me see the dose... (looking at the dose)..” “Sister (Loudly).. Sister..”

The Sister comes in.. “Please give Him one more bolus”. The sister nodded and gave him another bolus.

Mr Manoj was staring at the dose he was getting with a blank expression.

“You will feel better soon, and we will ensure you’re fully prepared before going home. If the pain comes back, you can always reach out to us. We’re here for you.”

As she stepped out, his son-in-law approached ..., “ Doctor... (With his eyes full of concern)..He started screaming again as soon as Dr. H mentioned discharge.” Dr. N nodded, determined to address Mr. M’s fears before proceeding.

“Oh Okay.. Mostly what will happen is the pain comes back and must be causing the sudden surge of pain but we will come back and talk to him again in some time.”

After some time....

Dr N went to Mr Manoj... “How is your pain?”

“ Silence.....Its okay now”

“Can I know what happened?”

“They are discharging me and I still have pain.. I am scared.. What if the pain comes back.? (Trembling)”

"They won't discharge you with pain and if they discharge you, we will admit you”

“Nodded.... With a small smile ... Thank you Doctor.. With tears in his eyes....he looked away towards the window, turned and slept.

Mr M’s discharge was postponed as he was still in pain and Dr N requested for a psychologist’s referral.

Shortly after being referred to him, I entered Mr. M's room. He was lying flat, his hand covering his eyes. His wife was also present.

“Hello, I'm Ann. I'm here to talk to you. Is this a good time?”

He nodded...with his eyes staring flat...I pulled the chair and sat next to him

“How is your pain?”

“He nodded and said," **It is better than before**” with a small smile.

Looking at his wife , I asked ,What is your routine like?

“Oh He likes To go for a walk in the Morning, Read newspaper, Take his grandchildren to school... Sometimes he also goes out with his friends”

Is It Mr M?

“Nodding... Looking blank.... **Now I don't do anything**”

Okay and why is that?

“**Nothing ... Looking at his wife and then away...**”

Do you want to Talk alone for some time?

“**No it's okay. Let her be here**”

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Okay and why is that?

“Nothing ... Looking at his wife and then away...”

Do you want to Talk alone for some time?

“No it's okay. Let her be here”

“ummm...Thats great.. I am glad you are feeling well...”

Silence... Yes

“Okay ... .Are you able to sleep now or... do you still get thoughts about your son in law ?”

“His face turned red...(trembling).... “What will I even say? He was like a son to me...(tears started flowing and now, I can't stop thinking about him.. Biting his lip... looking away.”

Wept for around 5 minutes... Silence.. Both are holding hands .

“I.....I've accepted I'm going to die, but I'm so worried about my grandchildren. What will happen to them without me?”

“Nodding...”

“I have already discussed it with my wife.. But still, don't know what will happen...”

“Okay... Can I know what you would like to have for your grandchildren..”

The following sessions were about the thoughts and feelings regarding his grandchildren and his dreams for them. Recognizing the depth of his concerns, we initiated family counselling

One of his daughters and her husband said, "Dad, we're all here for you, and and we are here to support chechi with her children"

“Crying.....Okay.. I know you all are there to support.. But it's just that she will have to handle everything alone.....I just want them to be okay “

His son-in-law added, “They’ll be fine, Dad. We’ll make sure of it.”

With their reassurance.. Mr Manoj was feeling calm “...I know all of you are there to help her and her children and I am happy about that... he held his wife's hand looking at her..”

Follow Up

As I walked in, he greeted me with a warm smile.

“How are you, Ann?” he asked.

“I am good, thank you. How are you feeling?”

“Much better.....They’ve planned for my discharge.”

“Oh, that’s great....smiling.

“I want to say thank you to all of you. I feel much better,” he said, reaching out to shake my hand. “I’ll see you soon... maybe.”

“Take care, Mr. Manoj ” I said warmly as we shook hands. “Wish you all the best.”

# Discussion points

Was there spiritual distress?

What were the cues for spiritual distress?

Could you place Mr Manoj in the spiritual distress trajectory ?

What are the various domains of distress ?

What facilitated the screening of Mr Manoj's distress?

Why did Dr N not explore the distress when she met him for the second time?

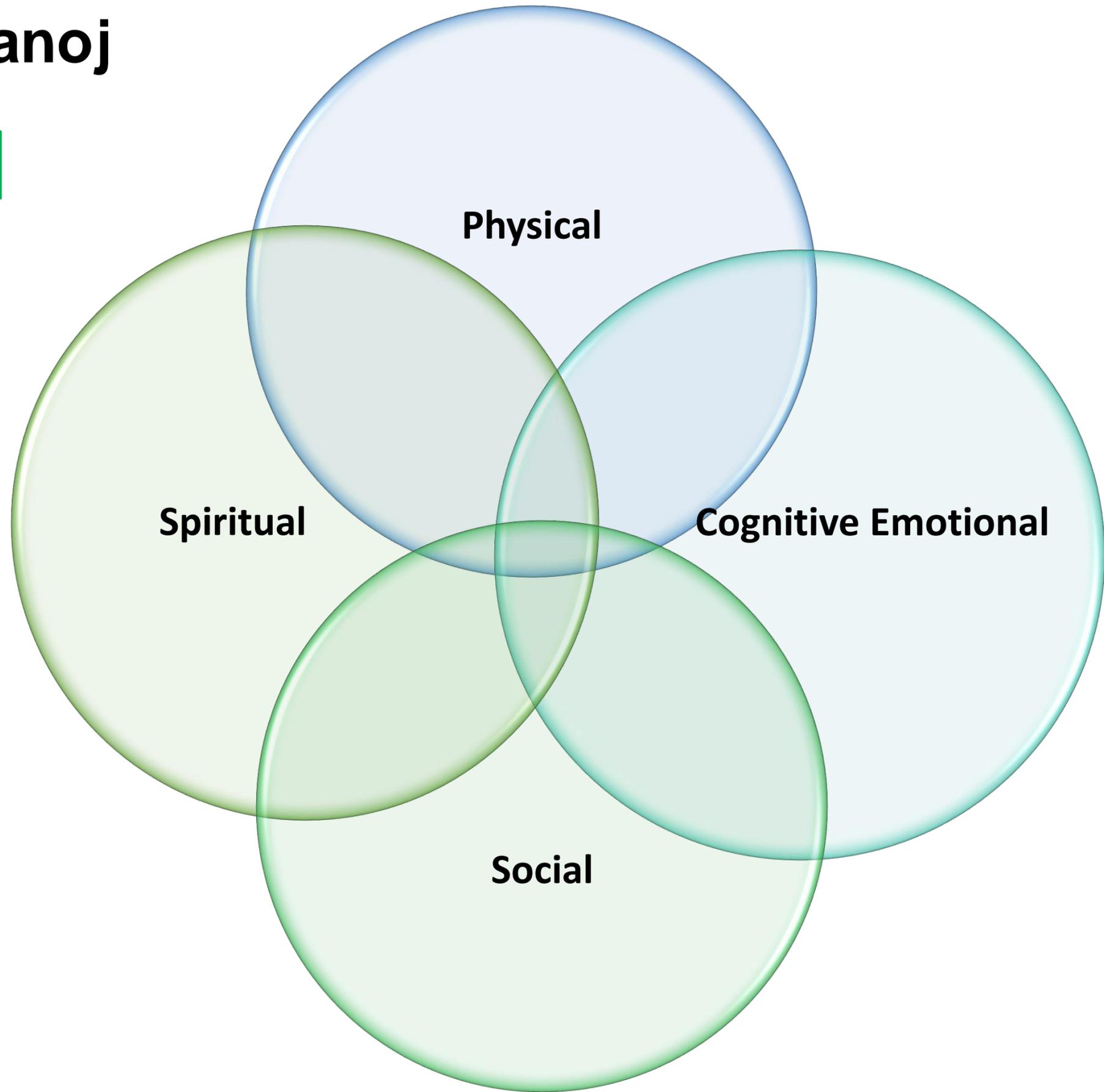
If you did not have a psychologist, how would you have dealt with this?

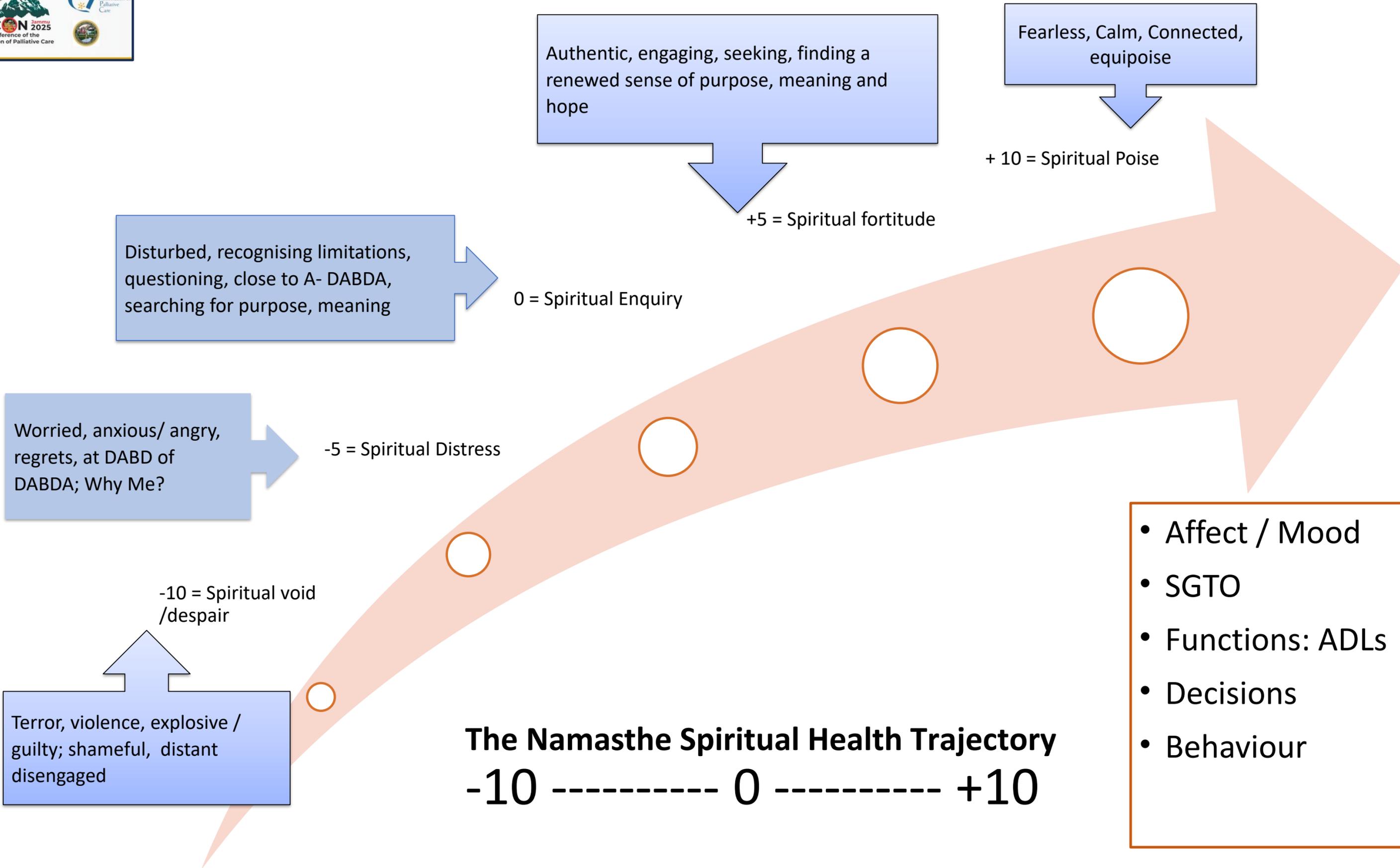
Can you identify some tools in this scenario that facilitated the discussion?

How did Ann respond when Mr Manoj spoke about death?

Is there anything you would have liked to do differently?

During Evaluation





Worried, anxious/ angry, regrets, at DABD of DABDA; Why Me?

Disturbed, recognising limitations, questioning, close to A- DABDA, searching for purpose, meaning

Authentic, engaging, seeking, finding a renewed sense of purpose, meaning and hope

Fearless, Calm, Connected, equipoise

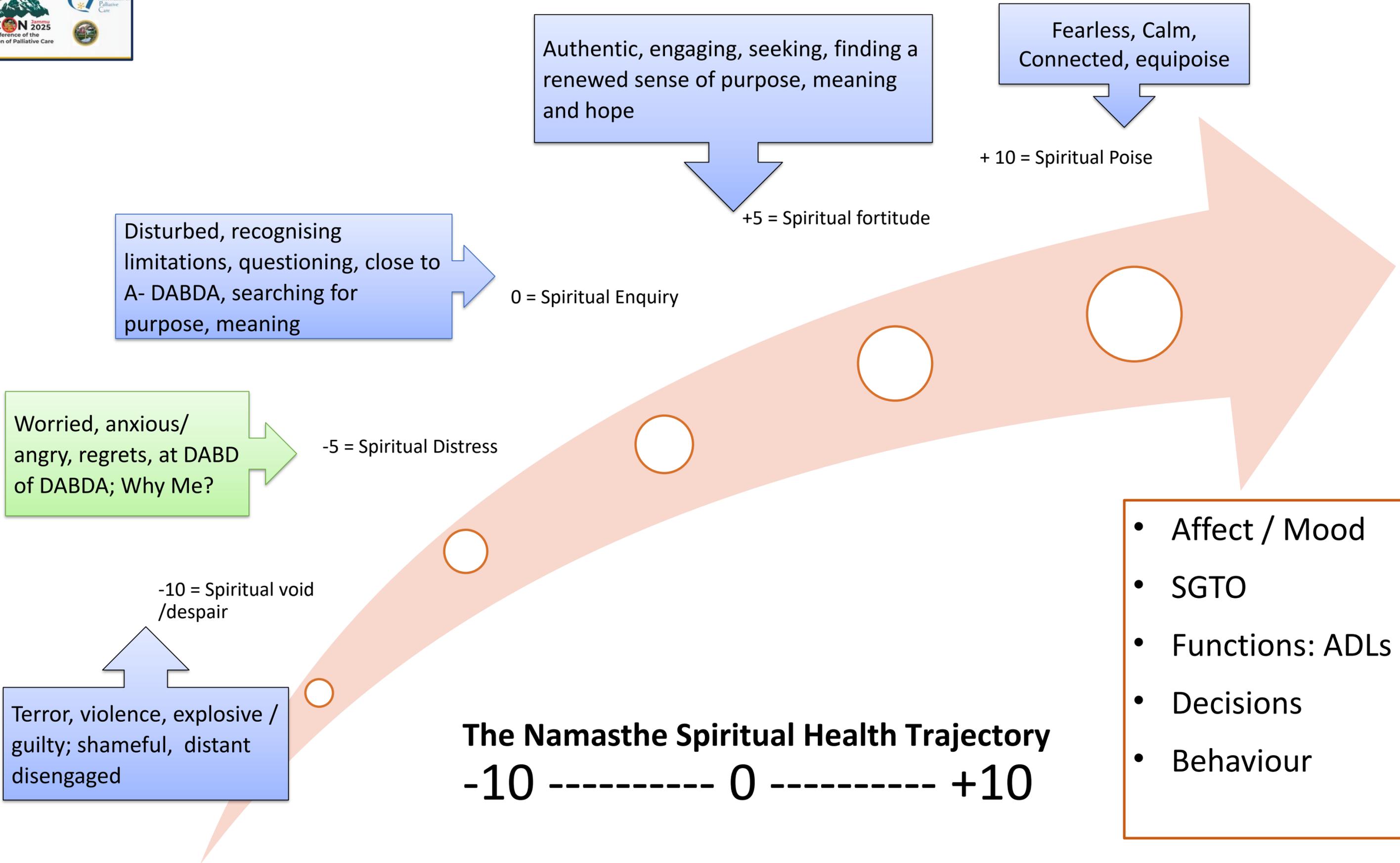
- Affect / Mood
- SGTO
- Functions: ADLs
- Decisions
- Behaviour



**Approach to  
managing Spiritual  
Suffering**

# The smile of *Uttara*

- Uttara walked in with a smile into our OPD
- k/c/o Medullary Ca Thyroid; Post- Surgery, then 33 # RT; on..Cabozantinib
- She had a Tracheostomy due to post-RT mucositis → respiratory distress.
  
- She C/O severe pain over the right hip NRS 9/10
  - Osteolytic metastasis over Iliac bones, trochanter, femur, sacrum, acetabulum, L4 body.
- CT chest – mediastinal, lung, liver metastasis.
  
- She was aware and shared the progressive nature of her disease, by blocking her Trach with her index finger.... maintaining her smile
- Comfort was her main goal and She had been advised to meet PC team, as the next step to care.
- She was accompanied by her husband of 20 years.



Worried, anxious/  
angry, regrets, at DABD  
of DABDA; Why Me?

-5 = Spiritual Distress

Terror, violence, explosive /  
guilty; shameful, distant  
disengaged

-10 = Spiritual void  
/despair

Disturbed, recognising  
limitations, questioning, close to  
A- DABDA, searching for  
purpose, meaning

0 = Spiritual Enquiry

Authentic, engaging, seeking, finding a  
renewed sense of purpose, meaning  
and hope

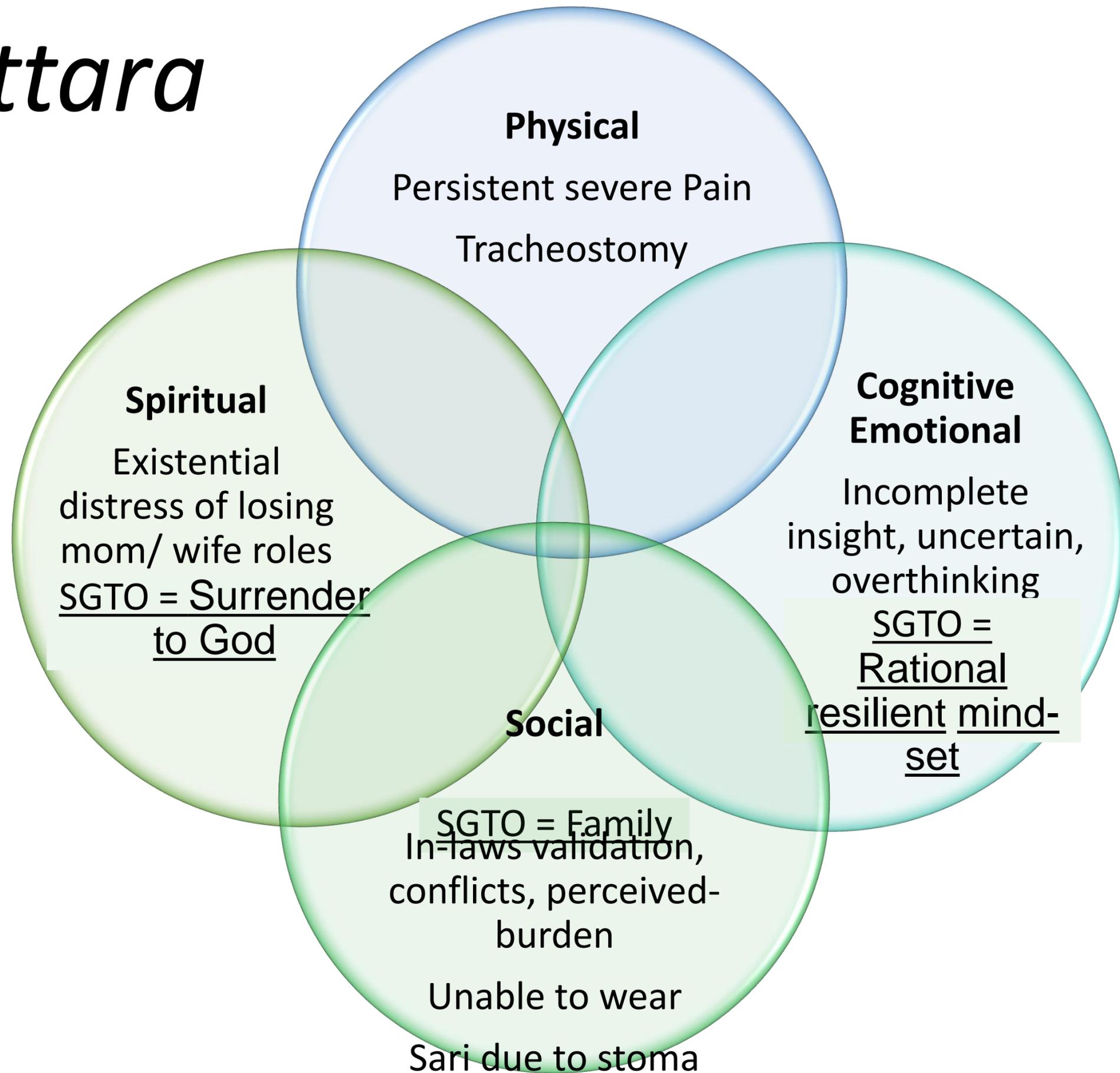
+5 = Spiritual fortitude

Fearless, Calm,  
Connected, equipoise

+ 10 = Spiritual Poise

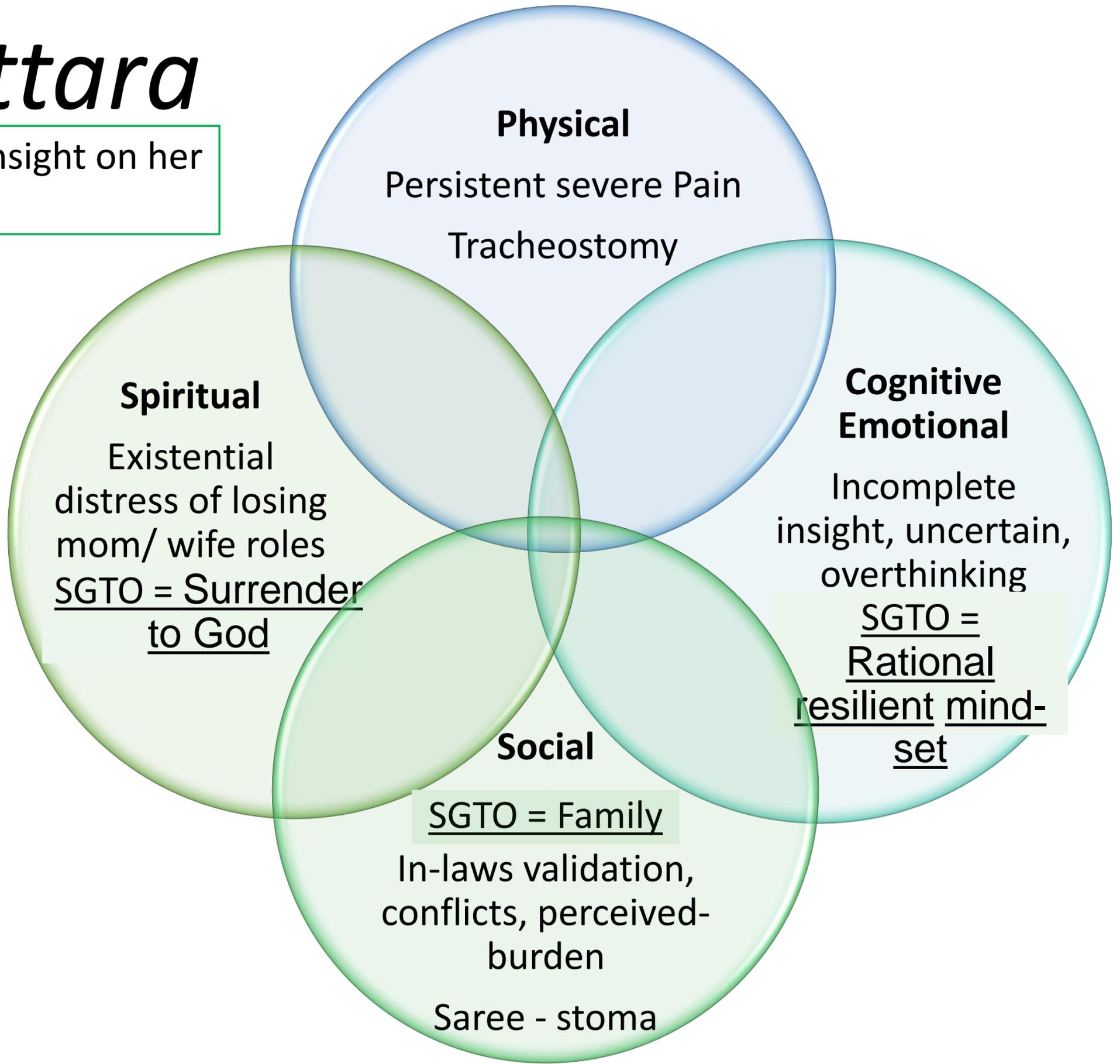
- Affect / Mood
- SGTO
- Functions: ADLs
- Decisions
- Behaviour

# Uttara



# Uttara

Once she had an insight on her  
Prognosis



*We noticed Uttara  
Truly smile 😊*

