

# Spiritual Palliative Care

Dr. Jochen Becker-Ebel

# Palliative Care Definition: Components of Care

**WHO 2002 (see: Indian Primer, page 4)**

**Others (see: India Primer, page 10)**

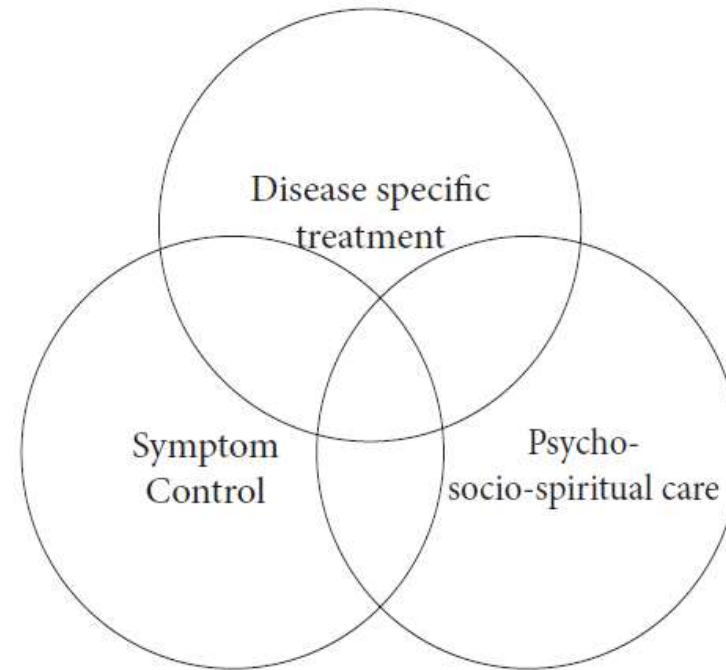


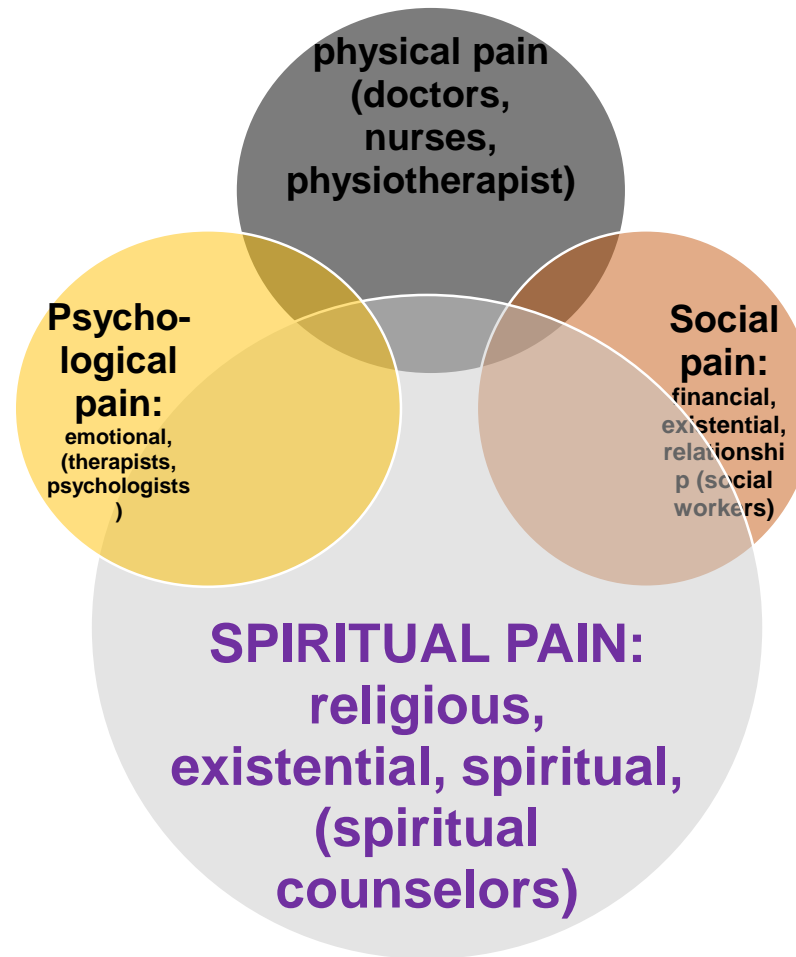
Fig 1.2 – Components of Palliative Care

# Example: UG Curriculum MBBS / nurses



A five modules some 160 pages curriculum for MBBS and a similar for nurses were handed in to the respective councils for approval and inclusion in the UG studies in 2013.

## II. WHO and other Definitions



# WHO definition on palliative care

**Palliative care** is an approach that **improves the quality of life** of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable **assessment** and **treatment of** pain and **other problems**, physical, psychosocial **and spiritual**.



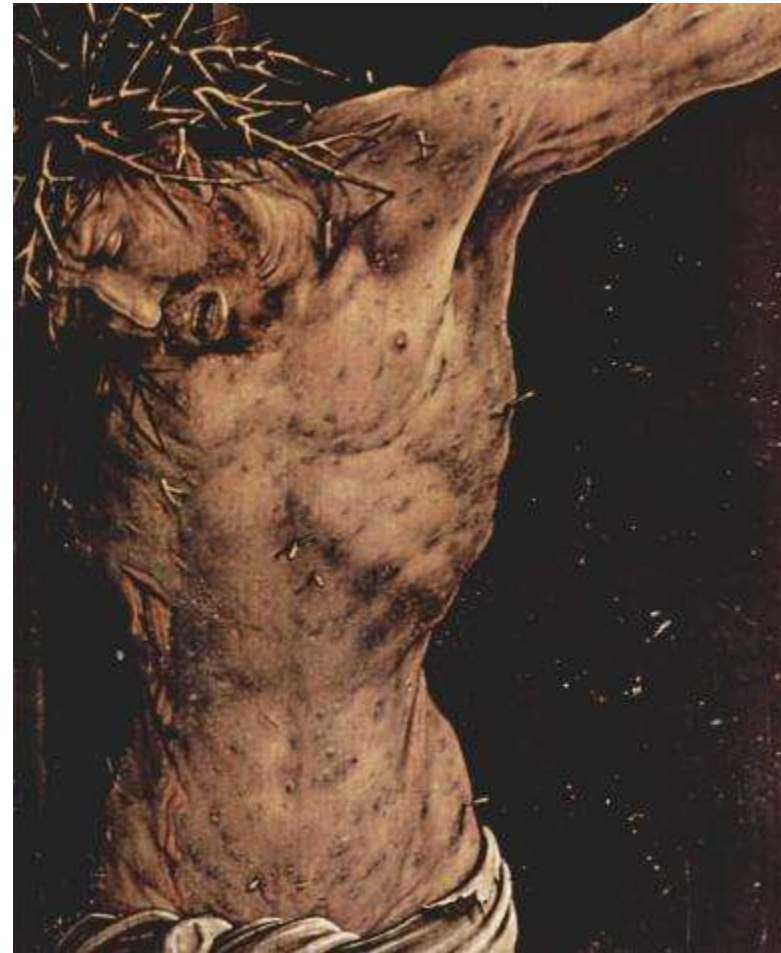
# I. Religion and Death: Buddha



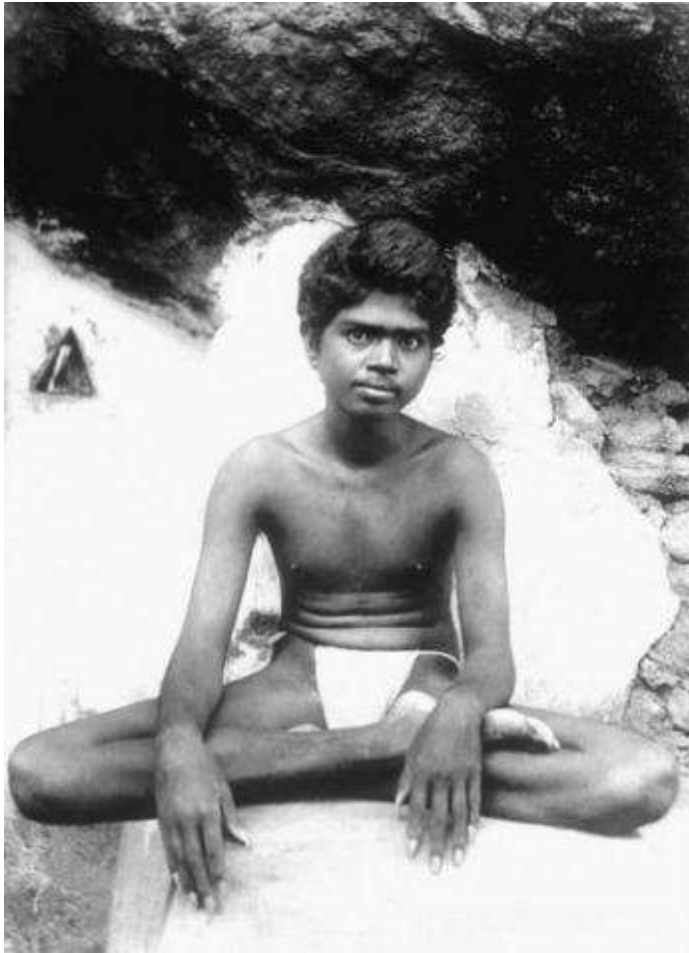
**Buddha** seeks liberation through overcoming death.

# Religion and Death: Christ

**Jesus** liberates  
believers through his  
death on the cross.



# Religion and Death: Ramana



**Ramana Maharshi's** experience: "I said to myself mentally: 'Now that death has come. What is it that is dying? This body dies. But is the body I?' . . . The body dies but the Spirit that transcends it cannot be touched by death."



# Conclusion on religion and death

Religion and Spirituality try to **overcome** (physical, body-related) death and pains.

They do not focus intensely on the pre-final period of life.

Therefore they do not give elaborate on precise answers in their central statements on **spiritual palliative care**.

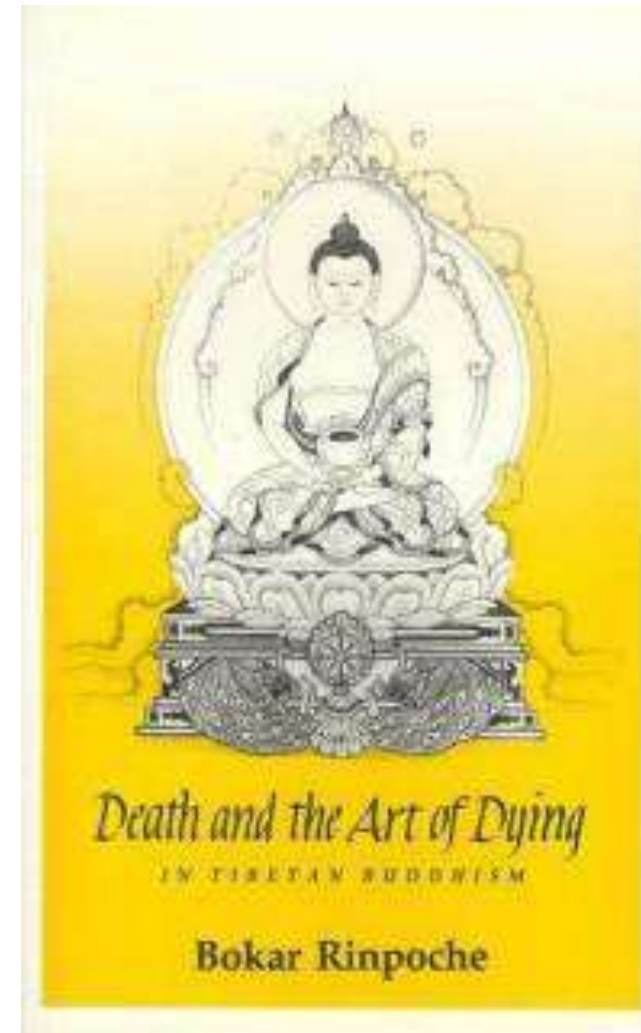
# Cure / healing

Most believers seek cure/healing when they pray. They want to overcome sickness.

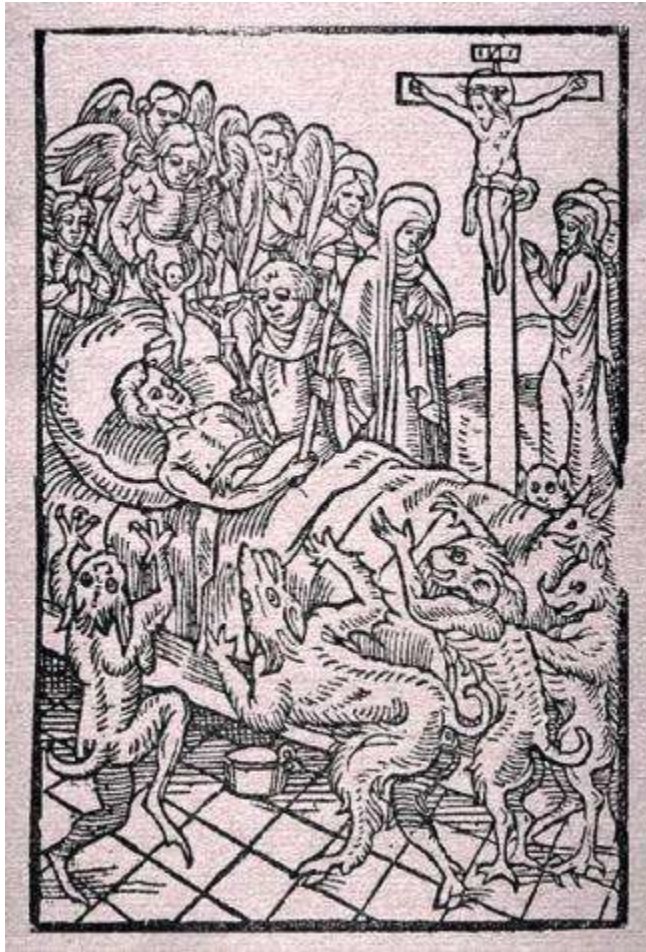


# Bardo Thodol

The **Tibetan Book of Death** gives help for those within the final moments of life or in first moments after death: “liberation through hearing during the intermediate state”.



# Ars Moriendi



In 15<sup>th</sup> century the Christian “**Art of Dying**” gave believers a more positive view on the process of dying and wanted to help them overcome fear and despair through faith, rituals and prayer.



# Near Death Experiences



Whether lack of oxygen or reality: Some person draw faith through near-death experiences and so they overcome fears.



# Conclusion

Religion did not elaborate intensely on the “art of dying” and the help for pre-final patients and relatives in their religious and spiritual needs.

Only after palliative and hospice care and clinical pastoral counseling movement came up some 50 years back religious and spiritual teachers put their mind into it on a structured way.

# Definitions on spirituality / religion

**Spirituality** is what gives a person's life meaning, how he views the world he finds himself in and this may or may not include a "God" or religious conviction.

**Religious care** relates more to the practical expression of spirituality through a framework of beliefs, often pursued through rituals and receiving of sacraments.

# Roll of spirituality in palliative care

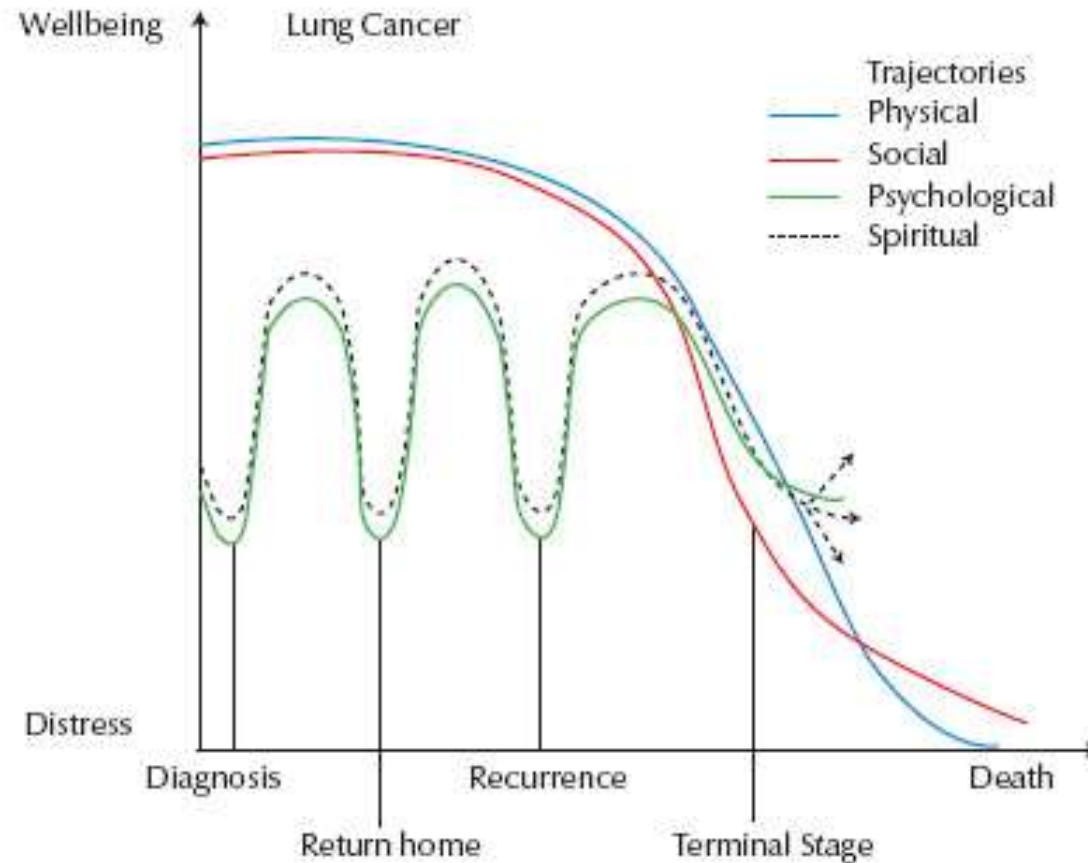


Figure 3 Lung cancer – physical, social trajectories and psychological, spiritual trajectories from diagnosis to death. Source: [24]

# Literature Overview 2010

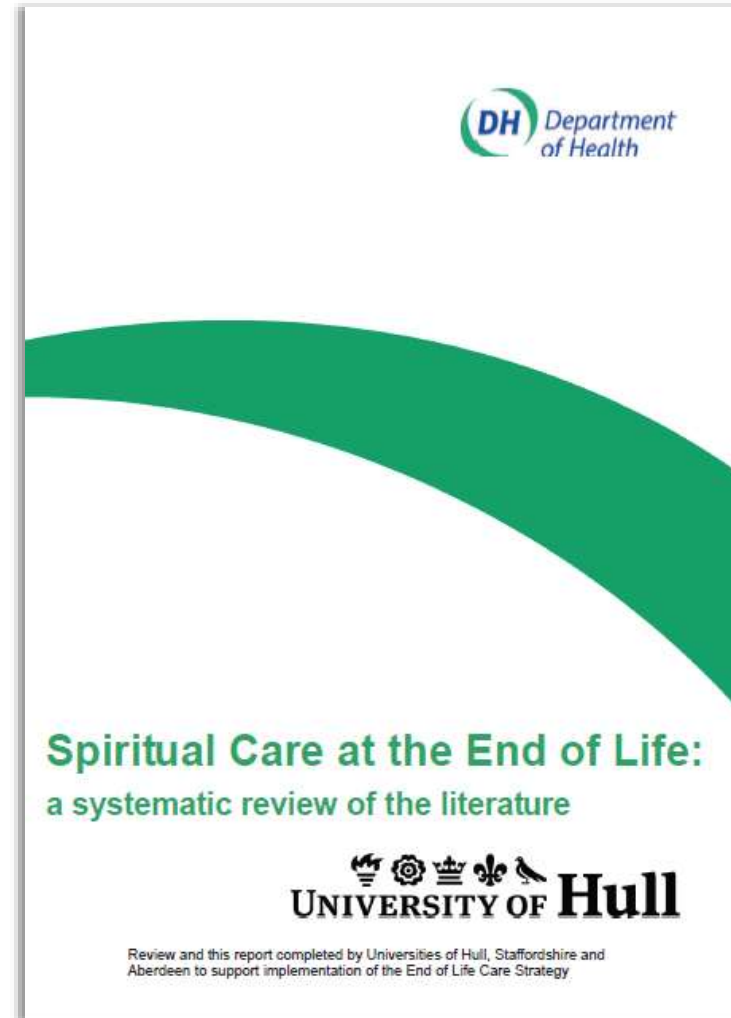
## **Spiritual Care at the End of Life:**

**a systematic review of the literature:**

[www.abdn.ac.uk/cshad/documents/SpiritualCareattheEndofLife.pdf](http://www.abdn.ac.uk/cshad/documents/SpiritualCareattheEndofLife.pdf)



Palliative Care Education



# Present Research (examples)

[http://edoc.ub.uni-muenchen.de/5433/1/Bauer\\_Stephan.pdf](http://edoc.ub.uni-muenchen.de/5433/1/Bauer_Stephan.pdf):

**a) Religious believers** do have in general **LESS** fear connected with dying - but only active believers with prior personal exposure to the topic.

**b) Religious/spiritual persons** with first exposure to an incurable cancer situation have **MORE** fear connect with dying than non-believers.

Munich University appointed a professor for Spirituality within Palliative Care in 2010.



Quality Indicator	Metric	Suggested Tools
<b>3. Outcomes</b>		
3.A - Clients' spiritual needs are met. <sup>16</sup>	Client-reported spiritual needs documented before and after spiritual care	<ul style="list-style-type: none"> <li>➤ Spiritual Needs Assessment Inventory for Patients (SNAP)<sup>17</sup></li> <li>➤ Spiritual Needs Questionnaire (SpNQ)<sup>18</sup></li> </ul>
3.B - Spiritual care increases client satisfaction. <sup>19</sup>	Client-reported satisfaction documented before and after spiritual care	<ul style="list-style-type: none"> <li>➤ HCAHPS #21<sup>20</sup></li> <li>➤ QSC<sup>1</sup></li> </ul>
3.C - Spiritual care reduces spiritual distress. <sup>22</sup>	Client-reported spiritual distress documented before and after spiritual care	"Are you experiencing spiritual pain right now?" <sup>21</sup>
3.D - Spiritual interventions increase clients' sense of peace. <sup>22</sup>	Client-reported peace measure documented before and after spiritual care	<ul style="list-style-type: none"> <li>➤ Facit-SP-Peace Subscale<sup>22</sup></li> <li>➤ "Are you at peace?"<sup>24</sup></li> </ul>
3.E - Spiritual care facilitates meaning-making for clients and family members. <sup>24</sup>	Client-reported measure of meaning documented before and after spiritual care	<ul style="list-style-type: none"> <li>➤ Facit-SP-Meaning Subscale</li> <li>➤ RCOPE<sup>26</sup></li> </ul>
3.F - Spiritual care increases spiritual well-being. <sup>27</sup>	Client-reported spiritual well-being documented before and after spiritual care	Facit-SP

# III. Spiritual need assessment

## **HOPE\***

H	Sources of Hope
O	Organized religion: level of identification or participation
P	Personal spirituality and Practices
E	Effect on medical care and end-of-life issues

## **FICA†**

F	Faith
I	Importance/Influence of faith or spirituality
C	Community: identification or participation in spiritual or religious community
A	Address/Apply: how to address patients' spiritual or religious concerns

## **SPIRIT‡**

S	Spiritual belief system
P	Personal belief system
I	Integration with a spiritual community
R	Ritualized practices and restrictions if any
I	Implications for medical care
T	Terminal events planning

# Assessment tools (Indianised) (1:1 interview)

FICA /SPIR Interviews (European Journal of Cancer Care 15, 238–243)

- *Spirituality*: Would you describe yourself as a believing/ spiritual/ religious person?
- *Place*: What is the *place* of spirituality in your life? How important is it in the context of your illness?
- *Integration*: Are you *integrated* in a group of spiritual believers/religious family?
- *Role*: What *role* would you like to assign to your doctor (or nurse or therapist) in the domain of spirituality?

# Examples - SPIR interview

- *Spirituality*: 'I am a believer in a broad sense. Whether it helps, I do not know.'
- *Place*: 'I find strength in my belief. Then I do not feel so alone.' 'God chooses strong people to deal better with the illness.'
- *Integration*: 'Although brought up in a strict religious background, I have nothing to do with institutional church.'
- *Roll*: 'I am glad that somebody is interested in such personal subjects.'

# Spiritual palliative care in (future) India



- Who are the “carers”?
- Will karma-concept, traditional rituals, holy places refuge help?
- Which impact has the religious diversity?
- What influence has “alternative healing”?

**There is more to listen, hear and learn on this.**



# IV. What can we do ???

## 1. Pray



## 2. Rituals



Recite holy texts,  
give Ganga-water / Tulsi leaf



Bless, holy ointment, Eucharist



### 3. Speak and listen







4. Meditate

5. Be present,  
be still,  
wait



# How to teach Spirituality in Palliative Care courses

Dr. theol. Jochen Becker-Ebel

Adjunct Professor for Palliative Care

IAPCON 2016 at Pune – Sunday Feb. 14th 9.30 am in Session 6A

**Empathy, Compassion and Spirituality: Need of the hour in medical teaching**

# Why to teach? –Patient, family & own needs

- God? ..... divine punishment/abandonment
- Self? ..... extinction of being/self
- Certainty? ..... “home”, foundation, “beyond”
- Why me? ..... meaning of sickness/pain
- Meaning? ..... loss
- Life balance? ..... negative

# What to be taught ? (..in India)

- Definitions & Spirituality as contribution to care
- Diagnosis: spiritual/existential needs of patient & help
- Done by each team member
- Own spirituality, rituals, mediation for care & self-care

All seems to be quite difficult and is often not done.

## 2. Palliative Care teaching in India (Raj 2012)

<http://ebookbrowse.net/teaching-palliative-care-in-india-m-r-rajagopal-ppt-d419648038>

### Palliative care practice needs..

- Heart (Attitude)
- Head (Knowledge)
- Hands (Skill)



Heart – part of learning

- emphasise with the patients emotional needs
- improve one's own communication skill
- understand one's own role in groups / teams
- Reflect on one's own work behaviour/ethics
- find one's own strength

<http://directfrommelissa.blogspot.in/>

 PallAction

Palliative Care Education



# Suggestions on: QoL, additional therapies 1

1. **supportive therapies: play**
2. music therapy: body tambura
3. Acupressure / Mediakupress®
4. Yoga: mudras, hatha yoga, take a minute™, pranic healing, laughter yoga



1. supportive  
therapies: play
2. **music therapy:  
body tambura**
3. Acupressure /  
Mediakupress®
4. Yoga: mudras,  
hatha yoga, take  
a minute, pranic  
healing, laughter  
yoga



1. supportive therapies: play
- 2. music therapy: singing**
3. Acupressure / Mediakupress®
4. Yoga: mudras, hatha yoga, take a minute, pranic healing, laughter yoga





# Suggestions on: QoL, add. therapies 3

1. supportive therapies: play
2. music therapy: body tambura
3. **Acupressure / Mediakupress®**
4. **Yoga: mudras, hatha yoga, take a minute, pranic healing, laughter yoga**

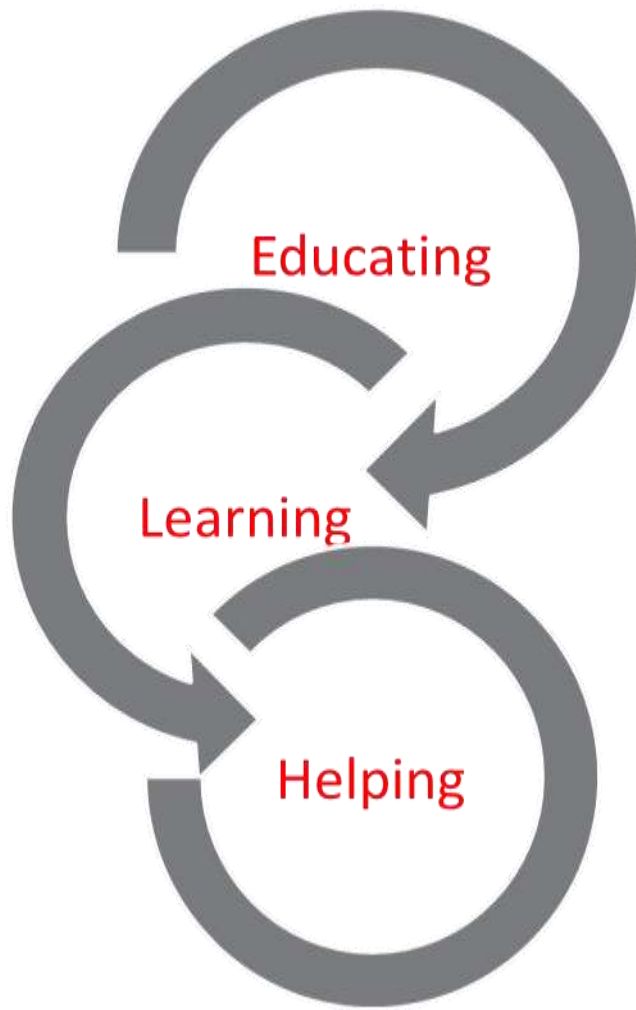


# Suggestions on: QoL, add. therapies 4

1. supportive therapies:  
play
2. music therapy:  
body tambura
3. Acupressure /  
Mediakupress®
4. mudras, hatha yoga,  
take a minute,  
pranic healing (Help  
Age) **laughter yoga**







Teaching means: not only know  
theory and practice, but...  
during teaching to cope with:

- emotions of the students
- outbreak of emotions, tears, grief,...
- resistance, non-cooperation, anger
- „knowing better“ or „have reason why this should not be done“
- students' lack of palliative practice
- conducting difficult group processes



**Rollplay**

# How (not) to teach?

**NOT: By long talks (all will sleep)**



**But: Through interaction methods**





# Rituals at teaching/conference (as sample)



# Work Impressions of 2016



KMC Attavar, Mangalore, Manipal University 3rd batch





Yenepoya University, Mangalore, College of Nursing; 3rd batch





Karunashraya with Bengaluru Network:  
NIMHANS, KIDWAI, St. Johns, NH, HCG a.o. for  
MD, nurses & counsellors: 1 day comm. course



# Background: Patients (caretakers) of Geriatric Palliative Care Ward, KMC Attavar, Mangalore

cannot ignore the issues of livelihood they are raising. "The government has to exclude beedi industries from the provisions of COTPA or restrict the Act only to

"None of the major trade unions including AITUC, BMS, HMS, CITU are in favour of including beedi under COTPA. Karnataka is one of the largest beedi man-

vanagere, Tumakuru, Chennarayana, Chamara, Harihara and Bengaluru. Beedis are produced in many pockets, and were previously exported even to first

The All India Cigar and Tobacco Workers Union is also incensed about the strict implementation of COTPA in the country. Activists of the union say

come together with other trade unions and ask the government to exclude beedi from the ambit of COTPA," said activist Mohammad Iqbal. In another dimension

states in his blog: "Non timber forest produce (NTFP) are important sources of livelihood throughout India. Tendu leaves play an important role

people during the off season, for collection of bidi leaves. The bidi industry has a vital role in rural welfare and in promoting the rural economy."

## Terminally Ill Octogenarian Inspires With Theatre Performance

Express News Service

**Mangaluru:** When 83-year-old Sumathi Pangal, playing the character of a headmaster in a skit, interrupts Lord Vishnu and justifies leading a life on her own terms, many in the audience could not help noticing that the skit was an expression of her personal thoughts about death and life.

The skit also came as a revelation of sorts to many, who wondered whether Sumathi Pangal, who is suffering from an advanced stage of cancer, was afraid of death.

The satirical skit, with heaven as a backdrop, ends with the headmaster not being sent to hell but back to Earth to lead a new life. The skit was staged during an unique programme, organised by KMC Nava Chaitanya at Shrusutha hall in KMC Attavar on Thursday.

Sumathi Pangal is confined to a wheelchair, but has not allowed cancer or a recent injury from a fall, to come in the way of her enthusiasm for writing and staging plays.

### Age No Setback

Thursday's programme was one among a dozen palliative care approaches envisaged for elderly people by Nava Chaitanya. The organisation has been founded by KMC professor of internal medicine Dr Prabha Adhikari M R and Jerardin D'Souza of the Mangalore Alzheimer's Association (MAA).

Dr Prabha felicitated both Sumathi Pangal and Lakshmi Rao Aroor. She informed that Lakshmi had served as the vice-president of Nava Chaitanya. "She played the role of the wife of Sumathi Pangal in all the skits staged to raise funds for some projects," Dr Prabha Adhikari



83-year-old Sumathi Pangal (Second from left), Lakshmi Rao Aroor and 102-year-old Michael D'Souza pose for a group picture after being felicitated at a programme organised by KMC Nava Chaitanya at Shrusutha hall in KMC Attavar on Thursday | EXPRESS PHOTO

recollected.

Lakshmi Rao, in her felicitation acceptance address, hoped to help others until her last breath.

The cynosure of attention was Michael D'Souza, who had come to the programme dressed in a blue suit with shining black shoes. The

gathering were left astonished when they were informed that D'Souza has completed 102 years.

"I still drive my Alto car

and there are no secrets to my longevity," said Michael, when the audience begged him to share his secrets on staying young and healthy.

### About KMC Nava Chaitanya

KMC Nava Chaitanya is an active aging centre, where elders perform exercises and do memory tests in order to prevent Alzheimer's Dementia (AD).

There are around 10 active aging centres with 1,000 members in Mangaluru.

The members have a great time as they go on picnics and celebrate all the national festivals like Republic Day.

Manorama Periera, comprising of mother and daughter team (Jayashree and Shruthi), perform wonderful dances.

"Their joy is to be seen to be believed," Jerardin D'Souza of the Mangalore Alzheimer's Association (MAA) emphasises.

MAA is an integral part of KMC Nava Chaitanya and acts as a support group, he added.

Farmers Will Ensure Victory of BJP in Panchayat Polls

16 Candidates

'Madhura

































# Spirituality thorough Action Methods: Preparing the work

## Starting the work



## Being prepared



# The „Persons in need“ and the „Carers“





# Preparing the stage



# Communication (students = trainers)



# The „Play of Gods“





# V. Accompanying the “inner growth”



Monika Müller, a German  
Spiritual Palliative Care Pioneer  
meets

Mr. B., a baker from profession,  
five days after hospital admittance  
with an unclear diagnosis





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