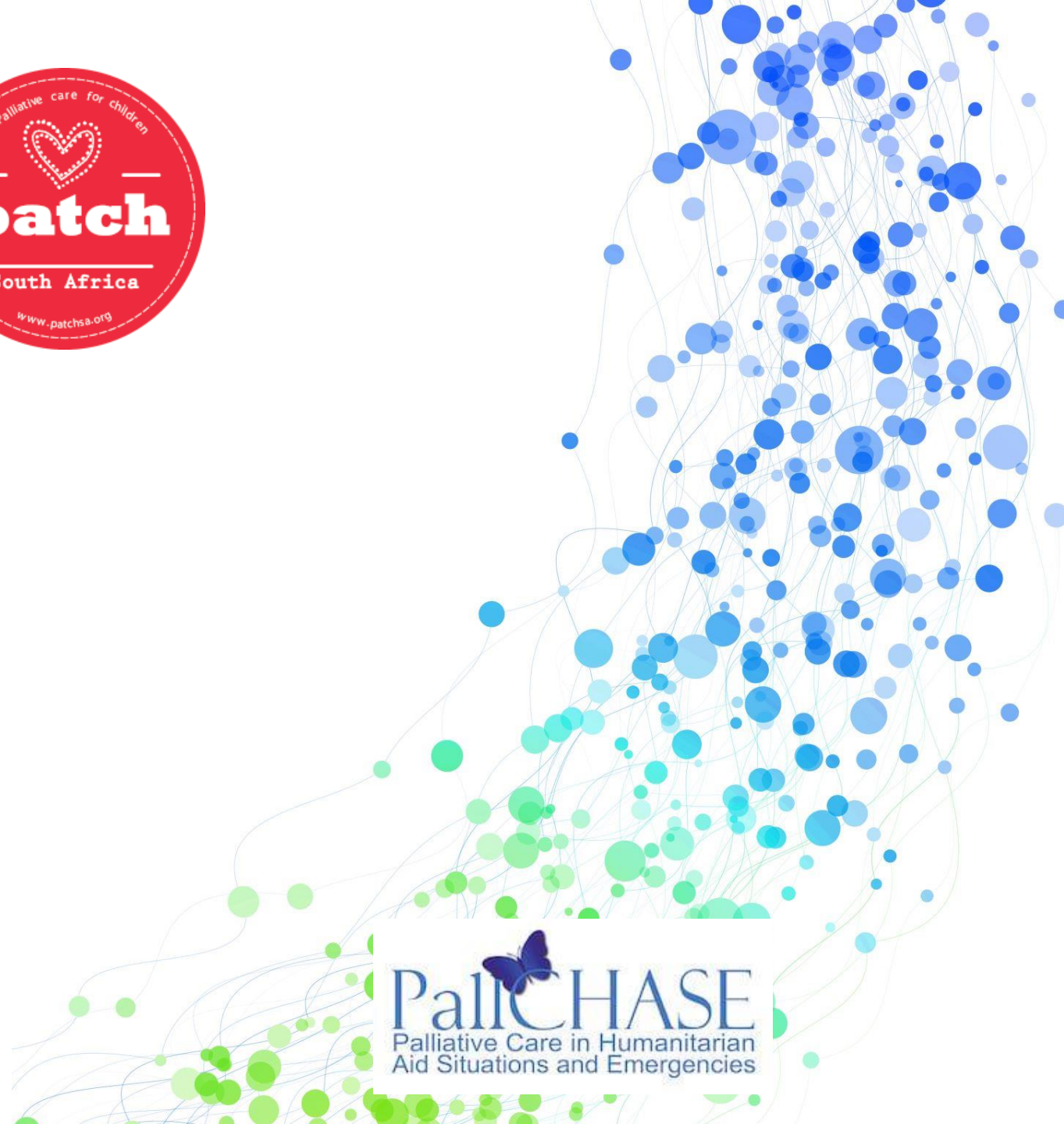


# Seeing the Unseen Spiritual Suffering in Children

Joan Marston

Canon Emeritus



# Let's think about the meaning of Spiritual & Spirituality



**We are not human beings having a spiritual experience. We are spiritual beings having a human experience.**

Pierre Teilhard de Chardin

*Body, Mind & Spirit or Spirit, Body, Mind?*

The goal of children's palliative care is the prevention and relief of suffering

Spiritual suffering of children requires the same attention, learning, skill and development of expertise as any other aspect of palliative care.

Spiritual Counsellors / Chaplains are essential members of palliative care teams

We must ensure that spiritual care is part of every Care Plan including Advance Care Plans

Refreshing our understanding of the meaning of  
Spiritual, Spirituality & Religion

Setting the scene -

How we need to be

Signs of spiritual suffering in different age groups

Steps in the process

Formal and informal Tools we can use



# And we need, and are the “Tools”

- History documents for guidance
- Awareness of our own spirituality and history
- Communication skills with children of different ages
- Ability to play , to listen, to observe
- Caring, accepting, loving presence
- Spiritual Care Plan



What does it mean to be dead Sr Joan?

# An International Consensus Definition of Spirituality

“Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek **ultimate meaning, purpose and transcendence and experience relationship to self, family, others, community, society, nature and the significant or sacred.**

Spirituality is expressed through **beliefs, values, traditions and practices.**”

Puchalski, C. M., Vitillo, R., Hull, S. K., & Reller, N. (2014). Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus. *Journal of Palliative Medicine*, 17(6), 642–656.

## Religion- from the Latin *re (again) ligare – to bind*

- Belief in a supernatural Being or Beings
- A particular system of faith and worship
- Has a communal and external aspect that involves rituals and structure and an internal aspect that is spirituality
- People with similar spiritual beliefs often gather together for structured and systematic expression of their spirituality

Spirituality is the Journey; Religion *may be* the mode of transport. *Dr Anne Merriman*



# The Essence of Spirituality is Relationships & Connections

***What gives life Meaning & Purpose***

***Positive Connections – with self, others, nature,  
Creator***

***Experience of Transcendence***

Transcendence comes from the Latin prefix trans-, meaning "beyond," and the word scandare, meaning "to climb."  
When you achieve transcendence, you have gone beyond ordinary limitations.



Every child is unique,  
different & developing

They have a connection  
with the transcendent

**WE NEED TO USE  
DIFFERENT APPROACHES  
AND TOOLS ACCORDING  
TO EACH CHILD**



As children develop they show different spiritual characteristics and need different types of intervention

*From a predominantly sensory and motor relationship* with their environment that requires maximum physical comfort, familiar persons, consistency and transitional objects like toys (0-2yrs)

*Through magical and animistic thinking where rituals* may be important and they need care, support and truthful explanations (2-12yrs)

*To a more concrete adult generality of thinking* where they search for meaning and purpose; hope and values; and may have an evolving relationship with a Higher Power.(12-18 yrs)

# Children have



- ❖ A recognition of the transcendent
- ❖ A way of living in awareness of the sacred
- ❖ A fascination for mystery and magic
- ❖ A sense of interconnectedness with others and with the real and the imaginary world
- ❖ A need for meaning and purpose

**Children are spiritual seekers** – but may not have the spoken language to explain this

They often use creative expression including play, art, poetry...

They need explanations in language they can understand -

We need to be creative in expressing our responses

Rabbi Sandy Eisenberg Sasso. God's Paintbrush



Humans universally have **basic spiritual needs** for Love, Faith, Hope, Integrity/ Virtue and Beauty.

Within these five needs are found both the fullness of our human spirituality and the breadth of our sources of spiritual suffering.

Spiritual suffering is experienced when these needs are unfulfilled.

Spiritual care involves assisting in the fulfillment of these needs.

Mark Bartel. 2015. What is Spiritual? What is Spiritual suffering

Dear God. here's a poem

I Love you  
Because you give  
us what we need to live  
BUT I wish you  
would tell me why  
you made it so  
we have to die.

## *Indications of Spiritual suffering :*

- Fear of loneliness or abandonment
- Non-acceptance of death or disability
- Unable to enjoy activities that previously gave pleasure
- Disconnection
- Fear of dying; death; the unknown
- Questioning
- Withdrawal

“The children are our teachers; we are the pupils.

It is a Master Class. ”

*Sr Frances Dominica –  
CPC Pioneer*



## Lesson 1:

A beautiful little girl, 2 biscuits and a ball



A little girl of 20 months HIV+ . Mother had died and she was placed in a Children's Home

Brought to Hospice Day Care

Appeared to have very delayed milestones - physically and intellectually

Appeared unable to walk, express emotion or attach to staff or other children. No eye contact.

Only comfort appeared to be from food



## Bella's Story

The Biscuit –  
the “Trigger”

The Ball – the  
“Connector”

The Nurse –  
the Connection

Lessons  
Learned:

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***1 Always, Always, Always take a full HISTORY***

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Bella had lived in a small, quiet room with her Mother, very few visitors . Despite their poverty, Bella was well-cared for and loved

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Placed in a Children's Home with other children, new people and activity noise

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Too young to understand the loss of her mother and her home she withdrew and suffered silently from multiple disconnections

## Lesson 2.

Find what is important to the child; assess possible disconnections & find a connector

***Bella was disconnected from :***

**Love** - from her mother

**Faith** – stability of her home

**Hope** – security of her life

***Her remaining connection to her mother was through FOOD and (we believed) a memory of PLAY***



# Steps in the History-taking and assessment process

1. Get to know the child and family so they feel comfortable – make a connection with the child through play, art, music, talk, bubbles, puppets etc
2. Ask a Screening question – and if they want to continue discussing this.
3. Take a History- use tools as guidance but not as a form to be filled- rather a conversation. This may take place over more than one interaction
4. Assess with someone with knowledge if you are not trained
5. Plan and implement interventions together with the child and family

# Screening

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**Depending on the child's age or level of understanding you may need to ask them or the family:**

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Is your spirituality/ religion important to you/ your child?

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Do you belong to a faith/spiritual community?

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Would you like to discuss this further?

Taking a History – FICA, BELIEF, HOPE other .....  
(a combination or your own ) whichever is best for  
the child and/or family

## **FICA**

Faith

Importance

Community

Address in Care



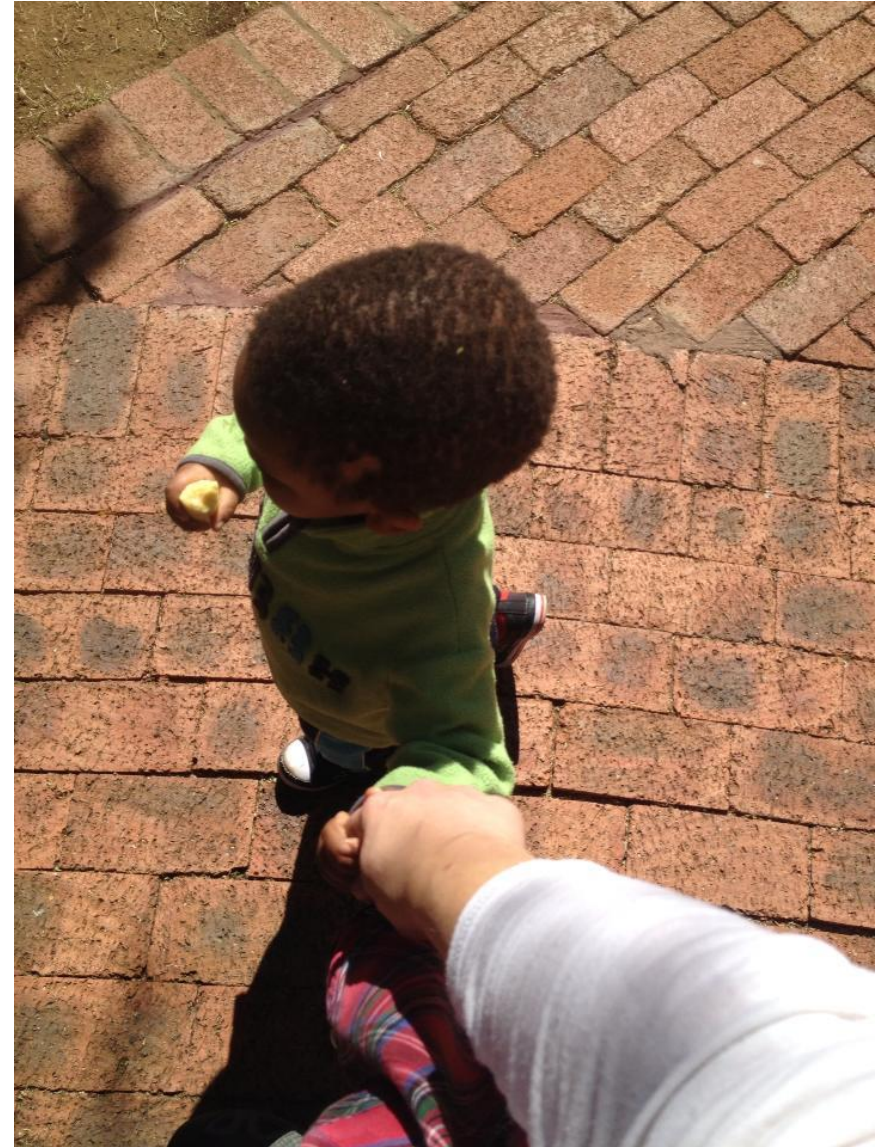
# The HOPE questions:

H: Sources of hope, meaning, comfort, strength, peace, love, and connection.

O: Organized religion.

P: Personal spirituality and practices.

E: Effects on medical care and end-of-life issues.





- B Beliefs
- E Experiences
- L Location
- I Involvement,
- E Education
- F Future

Susan 16 with an astrocytoma diagnosed at 10

Lost her hair and her sight in both eyes

Progressive muscle weakness and significant weight gain (steroids)

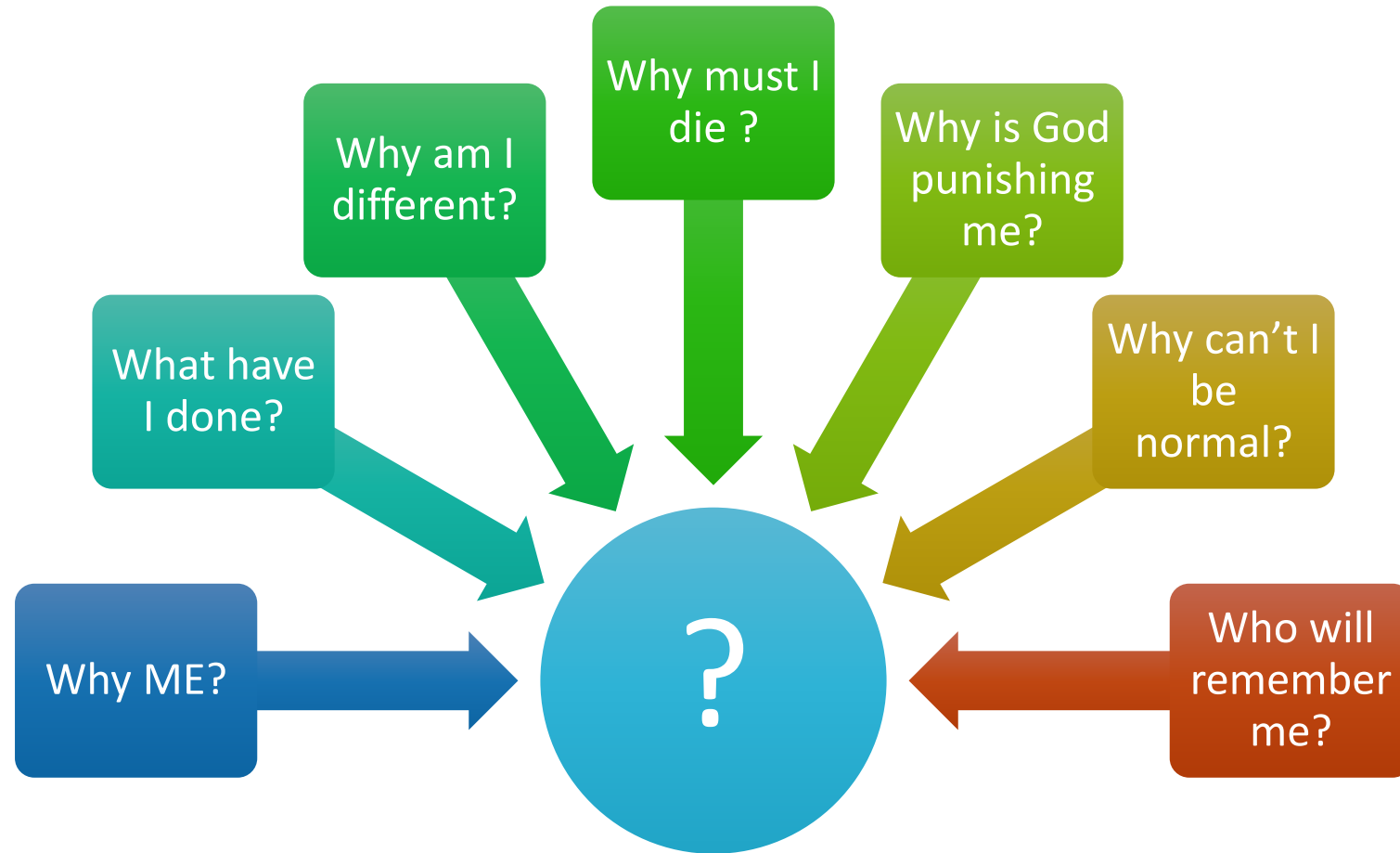
Anger outbursts especially at her older sister

An intelligent adolescent who missed school & normality

Susan expressed her suffering through a sensuous dance

# Who? Why? What? diagram

## Verbal older children and adolescents



Disconnected from all that gave her life  
Meaning and Purpose

Family

Friends

Fun

Church

School

Music



"How do these geese know when to fly to the sun? Who tells them the seasons? How do we, humans, know when it is time to move on?"

As with the migrant birds, so surely with us, there is a voice within, if only we would listen to it, that tells us so certainly when to go forth into the unknown."

Elisabeth Kubler-Ross. *The Wheel of Life*

# Stembi aged 3 realised he was dying

- Dying of heart failure, on oxygen, in bed and in distress
- He asked/ indicated to be taken to his favourite places and to see his favourite people
- Taken outside at night he pointed to a star and said “Stembi’s Star” (legacy)



Godfrey 10 loved to draw & told us he was dying although clinically he was improving



Modes of transport & empty swings

Things and places he loved

Pencilled in planes, rockets and helicopters in his bright pictures

“ I know I’m going to Heaven – but I don’t know how to  
get there”

## So many Questions

- Am I going to die?
- What does it mean to be dead ?
- Why me?
- What will happen to my body when I die?
- Why do I have to be sick /die?
- Who will remember me?





## Spiritual distress of the family:

- Feeling of a sense of emptiness
- Showing emotional detachment from self and others
- Expressing concern, anger, resentment, fear— over the meaning of life, suffering death
- Requesting spiritual assistance for a disturbance in belief system or faith

•(Puchalski, C. M. (2012). *Spirituality as an essential domain of palliative care: Caring for the whole person. Progress in Palliative Care, 20(2), 63–65.*)



The gift of Accompaniment

# Spiritual Care Training



**Interprofessional Spiritual Care  
Education Curriculum [ISPEC<sup>®</sup>]  
(VIRTUAL or IN PERSON)**

George Washington Institute for  
Spirituality in Health Care



Namaste

# Understanding ourselves

- Is your spiritual self important to you?
- Are you comfortable with your own spirituality?
- What do you do to nurture your spirituality and spiritual knowledge?

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Bettercare. Palliative Care for Children.2020 Patch Training Team. Ch 7

