

Managing End of Life Care in the critically ill child: Family, Legal and Professional Perspectives

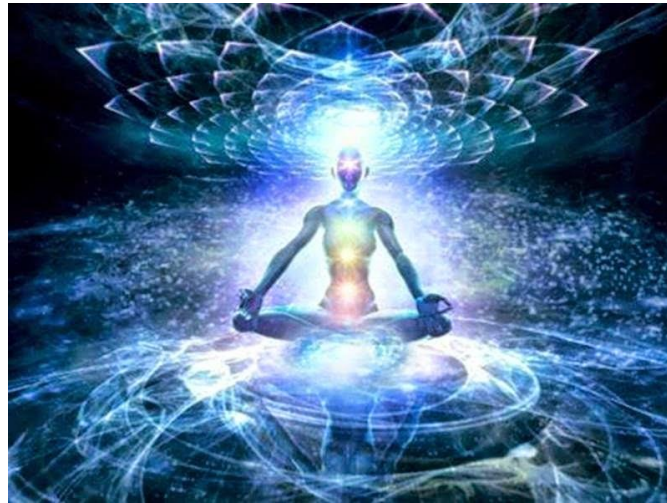
**Cultural and Religious perspectives
of End of Life Care**



In this session..

1. RCS Perceptions
2. Demystifying
3. Recognise Respect Respond

Perceptions





So what do you actually
do?

The Spirituality Enigma



- A consensus definition of spirituality continues to be ***elusive***. Gijsberts et al, 2011
- Patients were unsure of what was ***meant*** by the term 'spirituality' Best et al (2014)

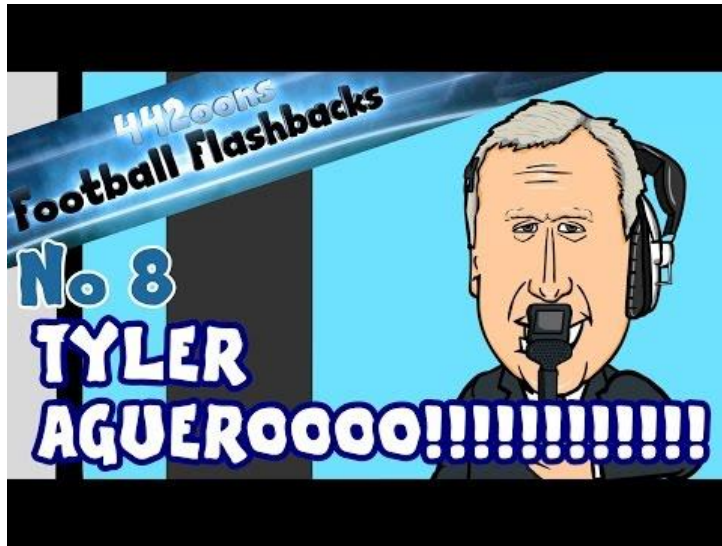
Demystifying



- Simply beyond definition?? (McSherry and Draper, 1998).
- ***`different meanings according to the present context a person finds themselves in.`*** Pike (2011)

“Spiritual”

“Am I a car?!”



Spirituality & Religion

- Synonymous...
- closely related.. (Speck et al, 2004).
- **the absence of religion does not signify the absence of spirituality**

To feel fragmented and objectified

*“It's never the same doctor, one becomes mad at this. You do not feel ... how do I say it, you do not feel human, but ... as an object on a **conveyor belt**, no one really cares. They have decided, medical science has determined, that's the way it is.”*

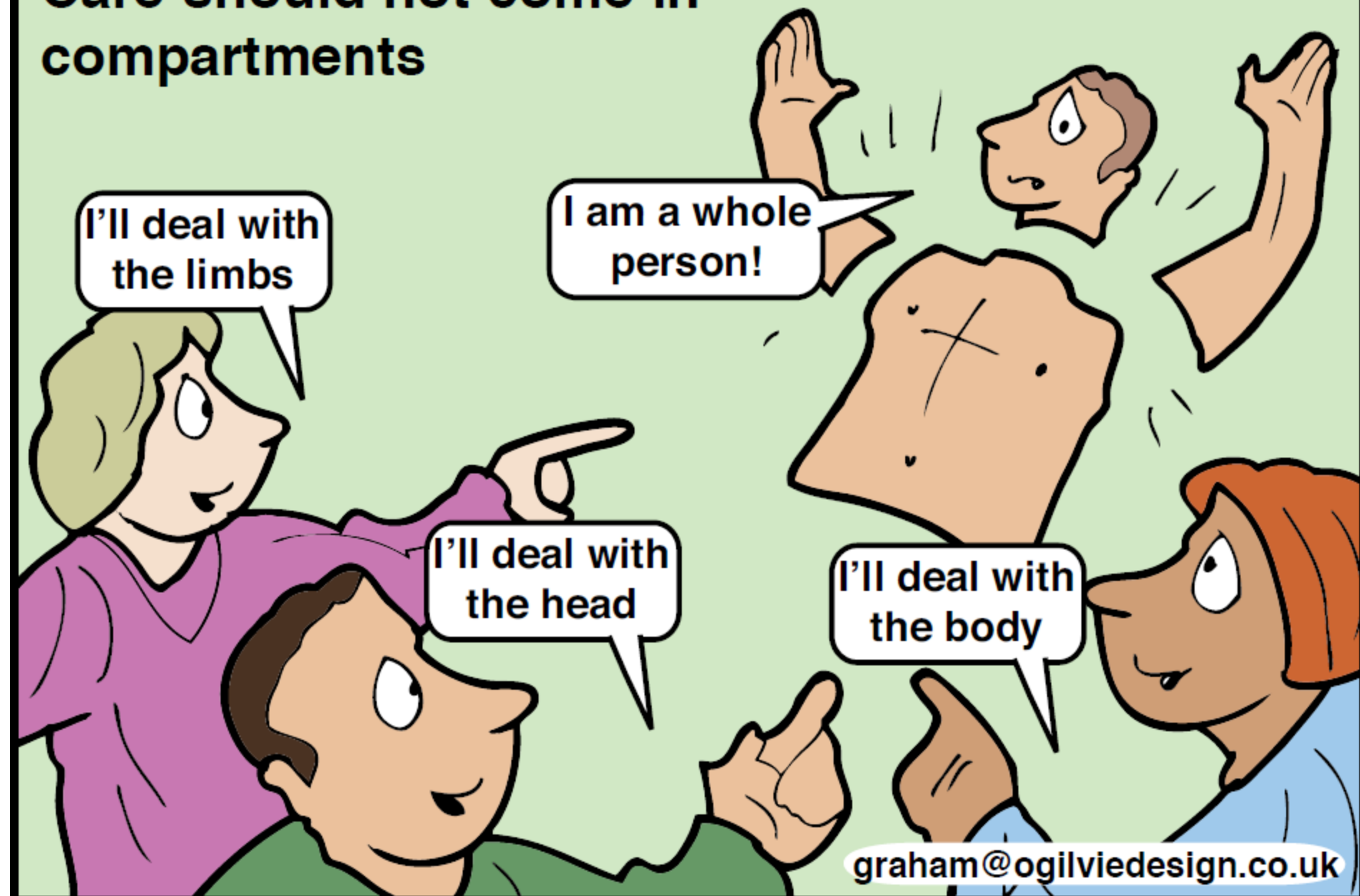
Suffering caused by care—Patients' experiences from hospital settings

Mia Berglund, Lars Westin, Rune Svanström, Annelie Johansson Sundler

Int J Qual Stud Health Well-being. 2012; 7: 10.3402/qhw.v7i0.18688. Published online 2012 August 27. doi: 10.3402/qhw.v7i0.18688



Care should not come in compartments





Holistic Healthcare



Person-centred care
Not
patient-centred health care

Dr Derick T Wade, Professor in Neurological Rehabilitation, Holistic understanding of health

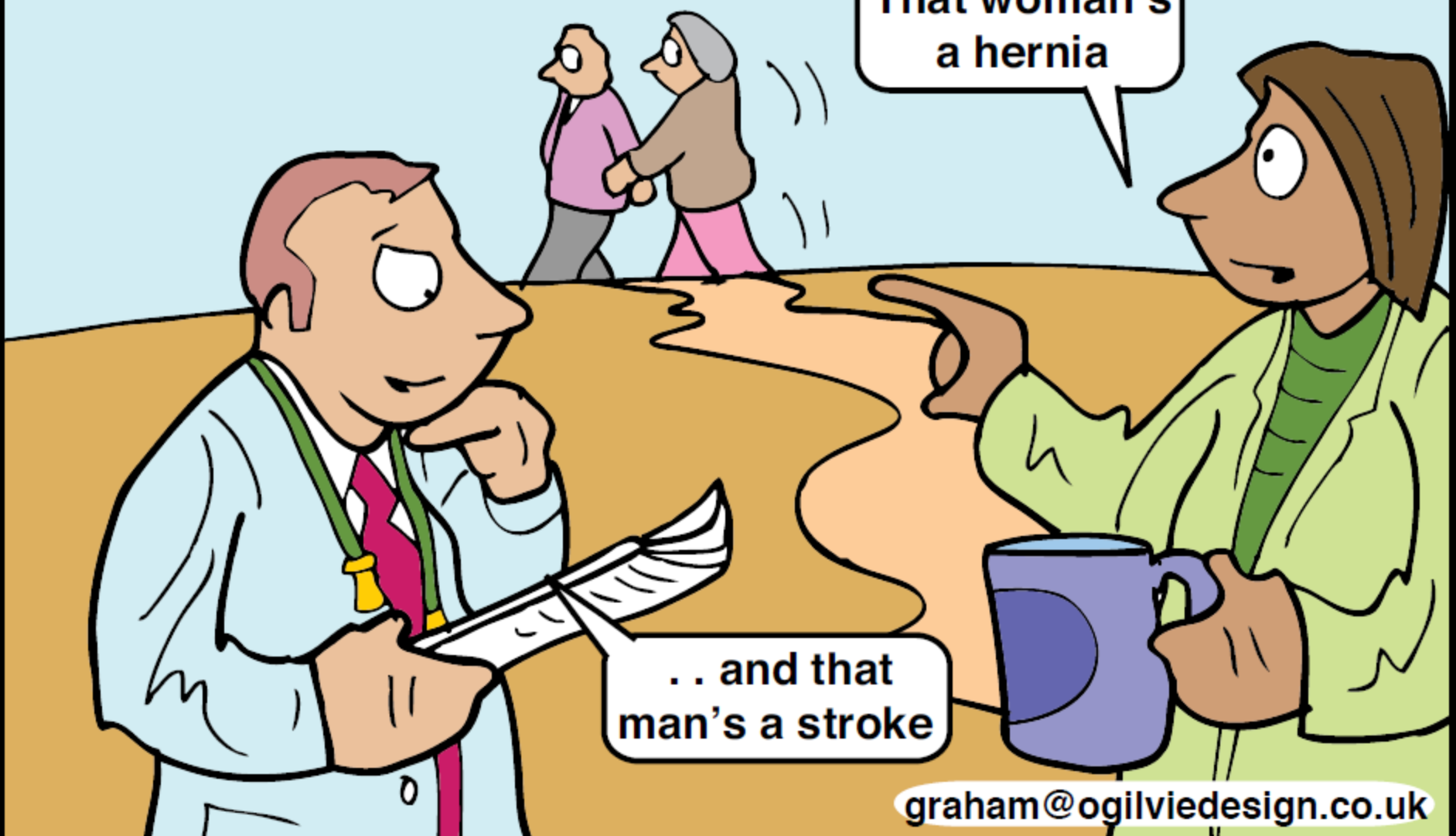


Too often, the medical profession can see people as symptoms

That woman's
a hernia

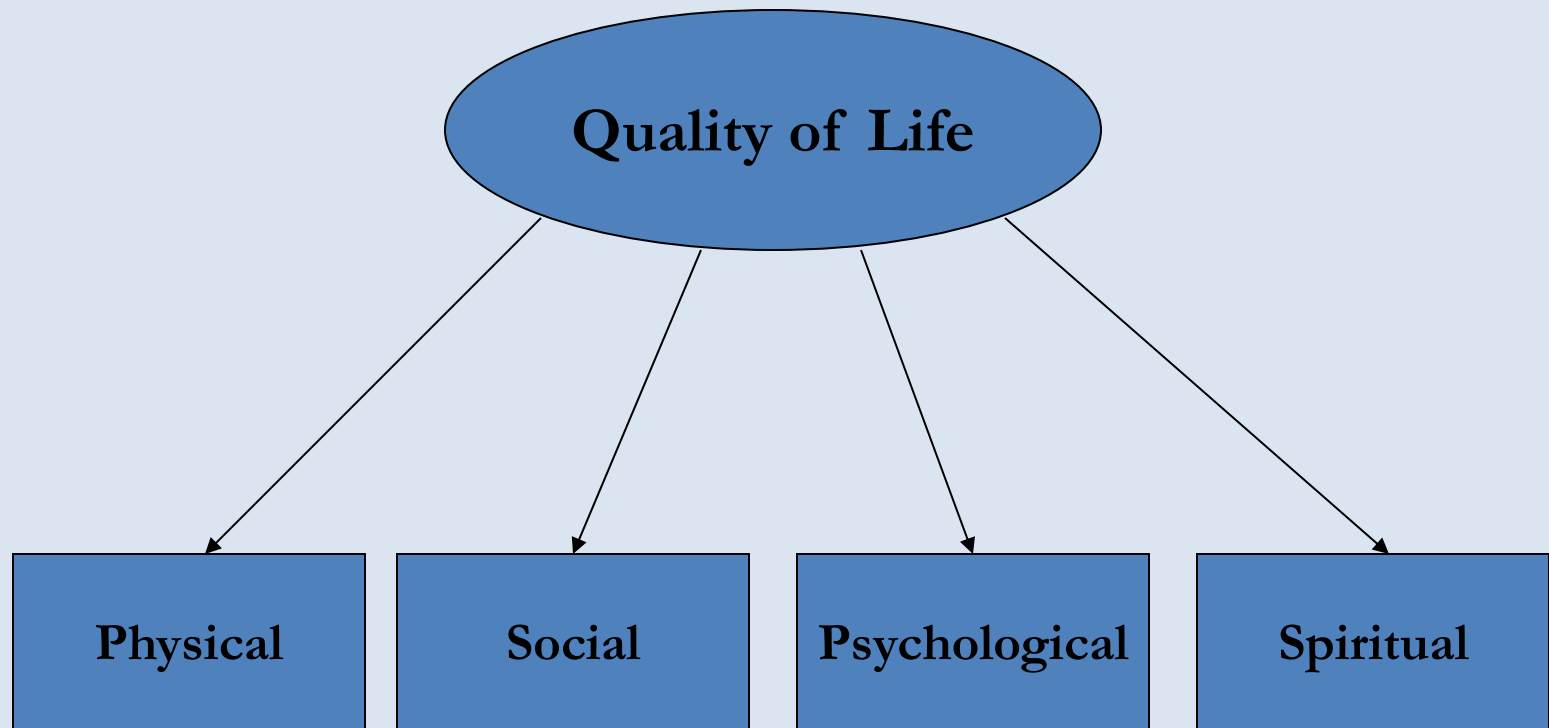
.. and that
man's a stroke

graham@ogilviedesign.co.uk



Spirituality and Quality of Life

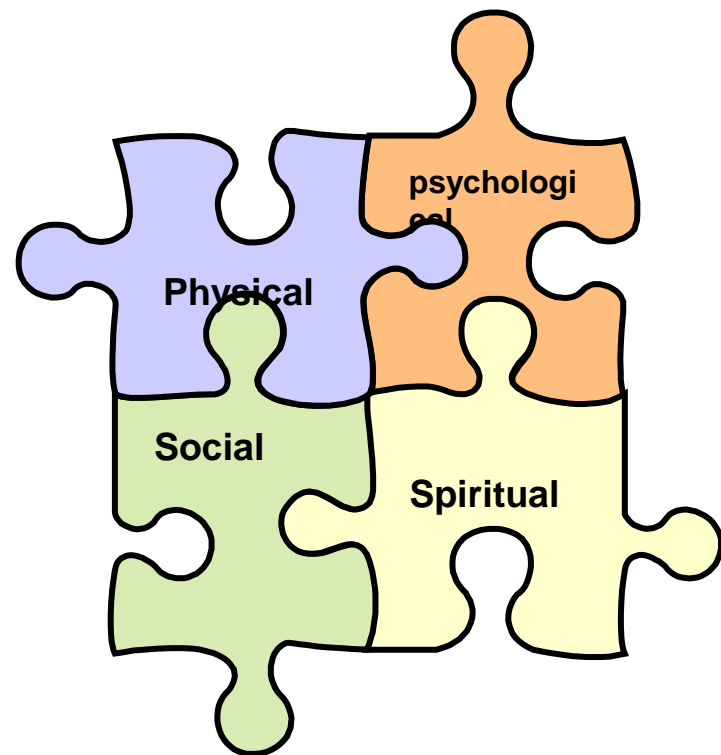
As a multidimensional framework



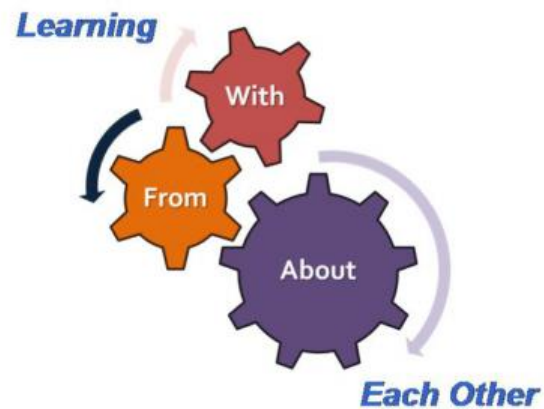
The biopsychosocial and spiritual assessment and treatment plan

Patient: Ronda is a 52-year-old with end stage ovarian cancer.	
Physical	Assessment: Pain is well controlled. Plan: Continue with current medication regimen.
	Assessment: Nausea; still has episodes of nausea and vomiting, likely secondary to partial small bowel obstruction (SBO). Plan: Add octreotide to current regimen.
Psychological	Assessment: Grief reaction that "fight is over." Tearful at times in visit but denies depression, no suicidal ideation, some difficulty sleeping but able to manage the sleep with music tapes. Reaction appropriate for her situation. Patient has strong coping skills and good support system. Plan: Supportive counseling, continue monitoring for worsening of hopelessness, ability to enjoy things, guilt.
Social	Assessment: Ronda concerned about how to tell her family that she is dying. While her relationships with her family are strong, Ronda is fearful of causing pain to her family. Patient has strong family support. Plan: Work with social work to arrange family meeting.
Spiritual	Assessment: Hopelessness, main source of meaning in "winning the fight", active in ovarian cancer alliance and seen as inspiration. This has been a source of hope. She has strong spiritual coping skills in past when husband died unexpectedly. Though not religious, she now wants to learn how "Jewish patients die?" Plan: Dream List, legacy building, encourage talking with Ovarian Cancer Alliance, referral to chaplain and to Rabbi.

This is a patient-based example of the biopsychosocial assessment and treatment plan, which incorporates the psychosocial and spiritual components.



MDT Working



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Isaiah Haastrup: 'God should decide' when baby dies

© 23 January 2018

f t b e Share



Isaiah, pictured with an aunt, suffered "catastrophic" brain damage, the court was told

Beliefs

Hope+Pray
= Miracle

"Everyone has the right to
freedom of thought,
conscience and religion."

—United Nations Universal Declaration of Human Rights

HOME » NEWS » HEALTH » HEALTH NEWS

Couple lose three of four children after judge orders removal of twins' life-support

A judge has ruled that a pair of twins with an unknown genetic disorder should have their life support switched off against their parents' wishes



The judge said no-one who had not been in the couple's position could appreciate their 'agony' Photo: Rex

By Agency

6:09PM BST 12 Oct 2015

A couple have lost three of their four children to an unknown genetic disorder after a judge ordered the life support for identical twins to be turned off against their wishes.



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Severely ill twin babies die after doctors turn off life-support machines against parents' wishes

The father told a court switching off mechanical ventilation machines was effectively 'killing the child' - against their faith



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COMMENTS

By [John Scheerhout](#)

11:43, 13 OCT 2015



./www.bettaliving.co.uk



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'It's the right right thing to do': Judge orders life support machine keeping toddler alive is switched off

Doctors said the boy was unresponsive and declared him "clinically dead" after he was rushed to hospital after choking on a satsuma



SHARE

By **Glen Keogh**

12:44, 16 FEB 2015 | **UPDATED** 12:53, 16 FEB 2015

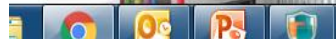
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**Are you a first
time buyer?**



**What the previous generation
found 'acceptable'
just won't do!**

Come, come now -
Doctor knows best . .

Err . . no - if you
want to know how
I feel - ASK ME!



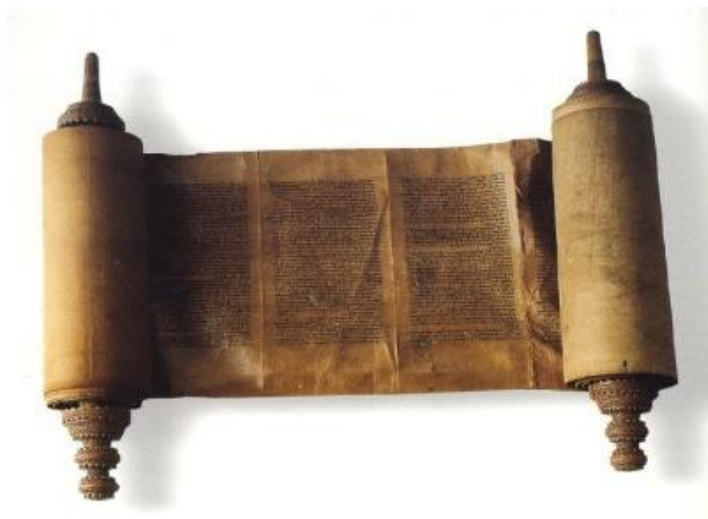
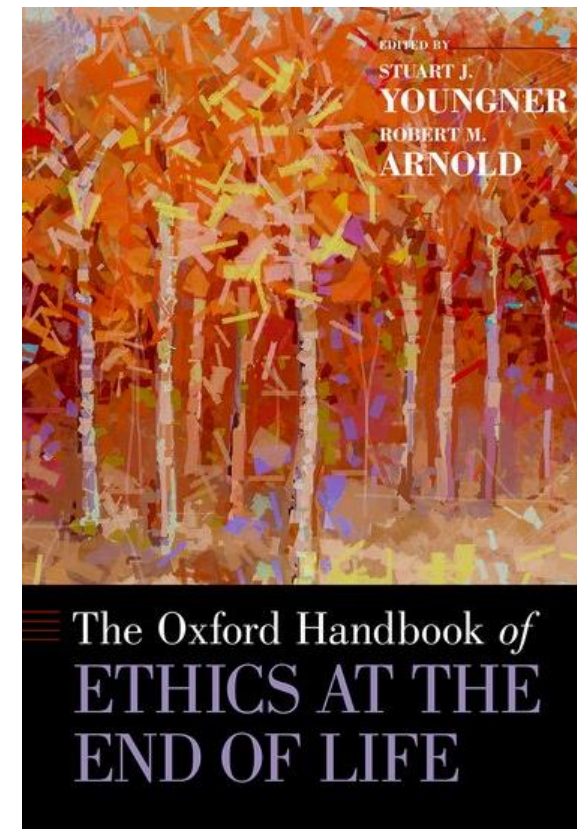
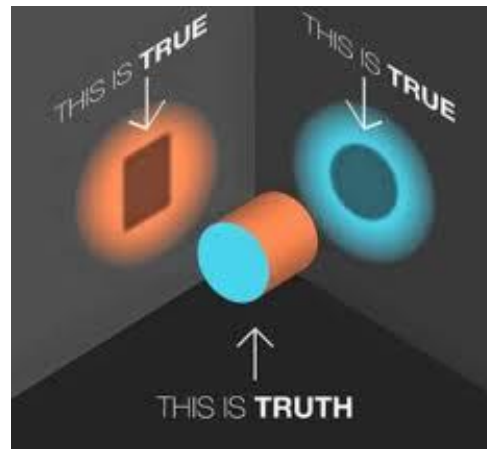
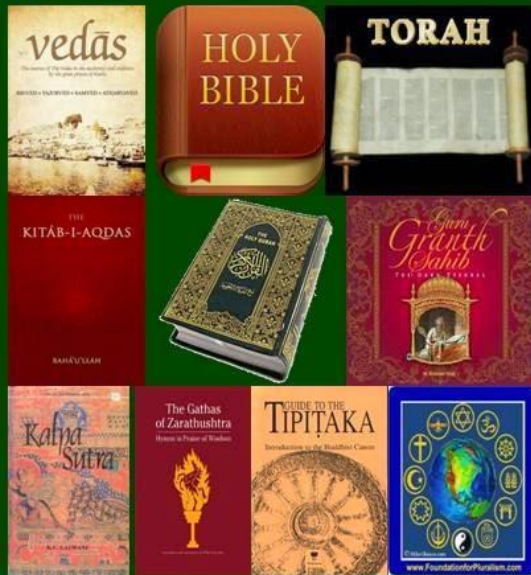
**WHO
DECIDES
?**



the child herself??



What are holy books for?



A framework for practice

Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice **FREE**

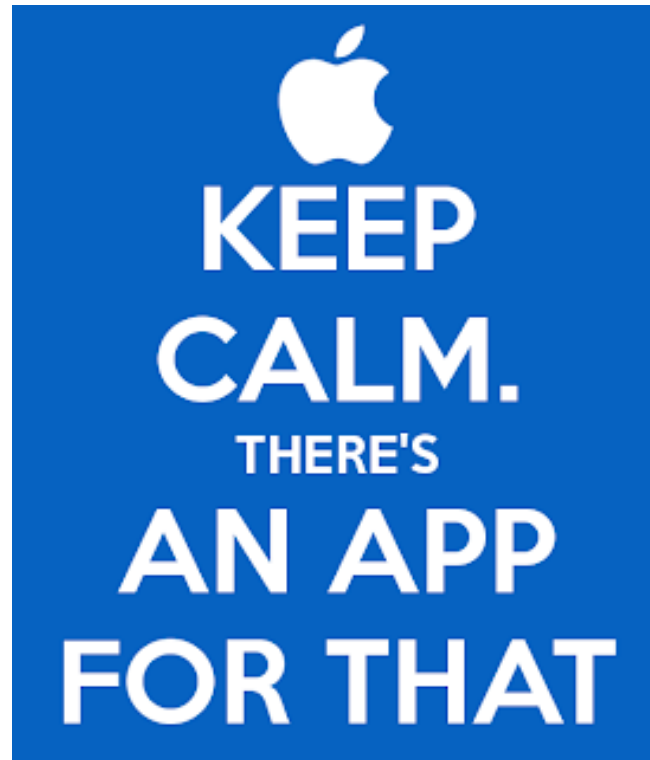
Vic Larcher¹, Finella Craig², Kiran Bhogal³, Dominic Wilkinson⁴, Joe Brierley^{1, 5}, on behalf of the Royal College of Paediatrics and Child Health

Author affiliations +

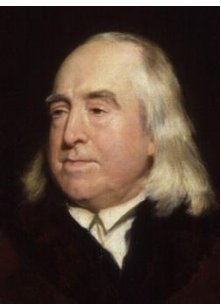
<http://dx.doi.org/10.1136/archdischild-2014-306666>



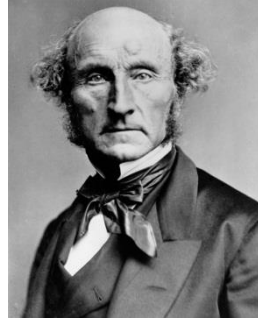
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A Reflective Framework



1. Utilitarian Approach

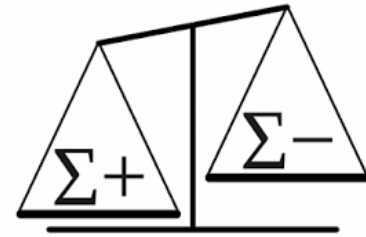


“The children are, in the opinion of the clinicians, cognitively unable to experience pleasure from comforting stimuli.”

a clash of philosophy between those who believe that

- if a treatment is available it should be used and
- those who believe that a treatment should only be used if it will achieve something

Utility



Which option will produce the most good and do the least harm?

Does this intervention produce more benefit and cause less harm/burden/risk for **all** who are affected?



2. The Rights Approach

“fundamental principles that undergird our humanity”

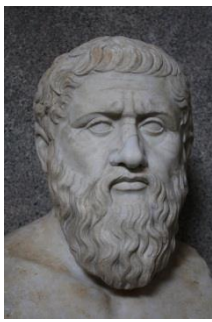
“They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism”

Rights

Which option best respects the rights of all who have a stake?



Does my intervention best respect the rights and dignity of all who have a stake?



3. The Common-Good Approach

"... there is a balancing exercise to be performed in assessing the course to be adopted in the best interests of the child

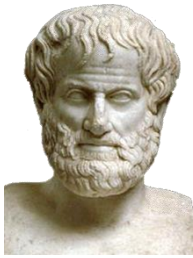
the problem of formulating the critical equation..."

Common Good

Which option best serves the community
as a whole, not just some members?



Does this intervention best serve the community
as a whole, not just some members?



4. The Fairness or Justice Approach

- But the sanctity of life is only one of a cluster of ethical principles which we apply to decisions about how we should live. Another is respect for the individual human being and in particular for his right to choose how he should live his own life. We call this individual autonomy or the right of self-determination. And another principle, closely connected, is respect for the dignity of the individual human being: our belief that quite irrespective of what the person concerned may think about it, it is wrong for someone to be humiliated or treated without respect for his value as a person. The fact that the dignity of an individual is an intrinsic value is shown by the fact that we feel embarrassed and think it wrong when someone behaves in a way which we think demeaning to himself, which does not show sufficient respect for himself as a person"
- Lord Hoffman then goes on to point out, however:
- ".....what is not always realised, and what is critical in this case, is that they are not always compatible with each other."

Justice

Which option treats people equally or proportionately?



Does this intervention treat people equally or proportionally?

5. Virtue

Which option leads me to act as the sort of person
I want to be?

virtue (noun)

a beneficial quality, feature or
trait leading to excellence;
advantage or goodness

Does this option lead me to act as the sort of
person I want to be?

Weigh the Perspectives

Change the values in each box to indicate how much weight you want to give to each approach.

1. Utility:

2. Rights:

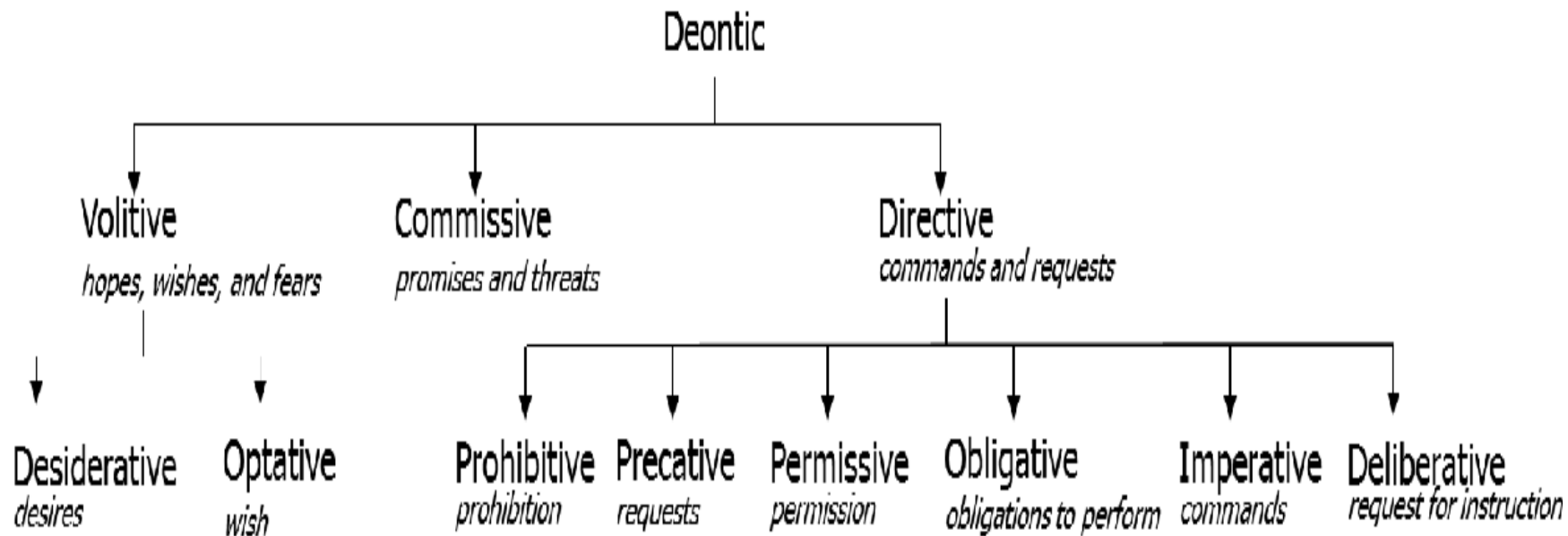
3. Justice:

4. Common Good:

5. Virtue:

Reflect!

"that could be defended in public if challenged"



Sub-categories of directive modality

Imperative / Fardh,

➤ Must!

Prohibitive / Haraam,

➤ must not!

Obligative / Waajib,

➤ ought to..

Precative / Mandoob,

➤ Will you?

Deliberative /

➤ Shall I?

Permissive / Mubaah,

➤ May you?

Disclaimer

This method, of course, does not provide an automatic solution to moral problems. It is not meant to. The method is merely meant to help identify most of the important ethical considerations. In the end, we must deliberate on moral issues for ourselves, keeping a careful eye on both the facts and on the ethical considerations involved.

Holistic relativism

- Holistic
- Relative



Questions are guaranteed in life;
Answers aren't.



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