







# The limits of consciousness

DEATH, FROM CELLS TO SOCIETIES: AGEING, DYING, AND BEYOND

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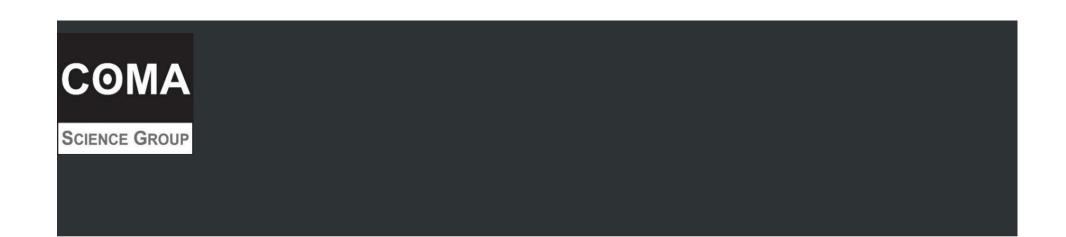


Dr Steven Laureys



#### OUTLINE

- 1. Consciousness & altered states of consciousness
- 2. Brain death
- 3. Unresponsive Wakefulness Syndrome
- 4. Ethics of death and dying
- 5. Near-Death Experience
- 6. Conclusion



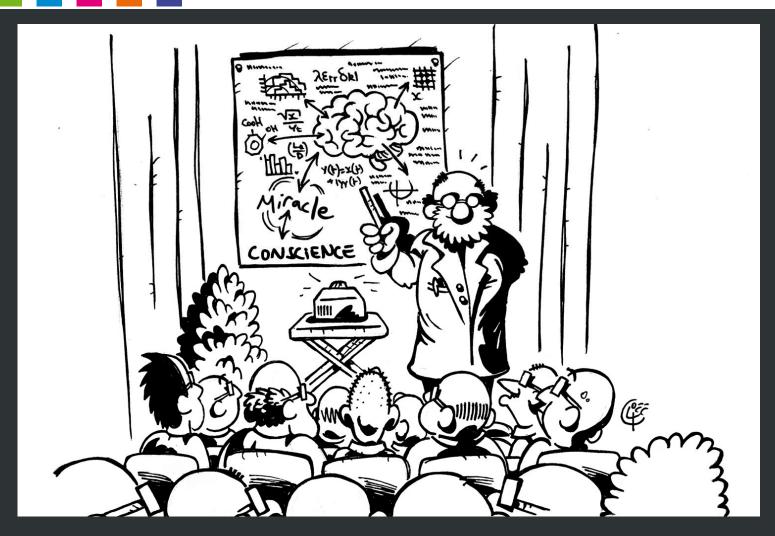
# 1. Consciousness and altered states of consciousness





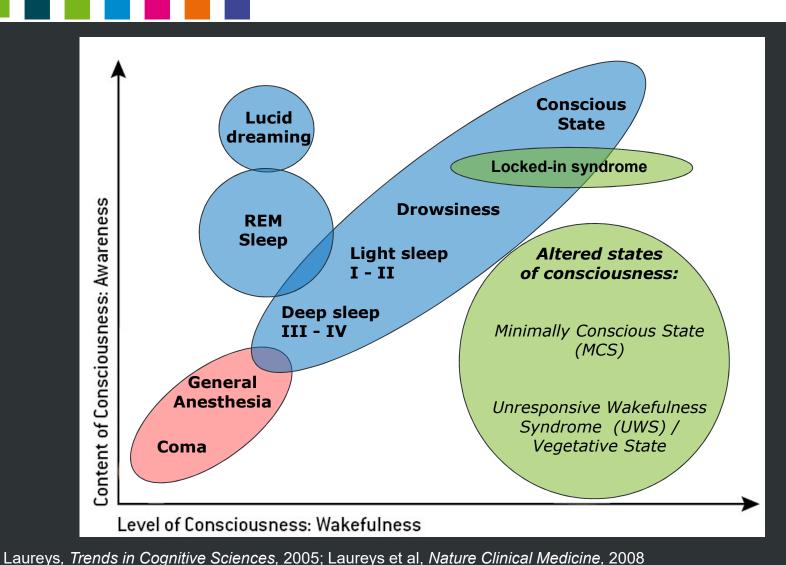
#### A definition of consciousness

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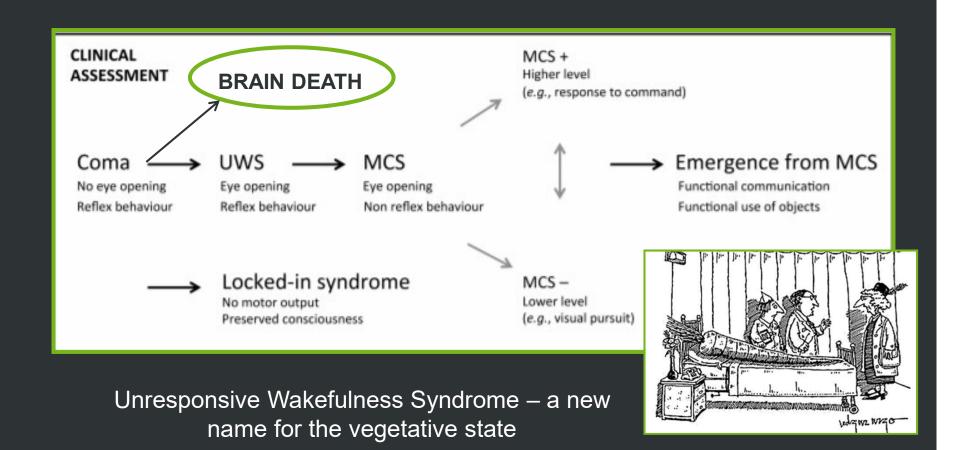
#### Reducing consciousness to 2D





#### Altered states of consciousness

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# 2. Brain Death





#### "I am dead "

LaMeuse.be

Régions » Liège » Actualité

Mis à jour le Jeudi 30 Mai 2013 à 13h26

Liège: un médecin belge au chevet d'un «zombie» en chair et en os





# WALKING DEAD

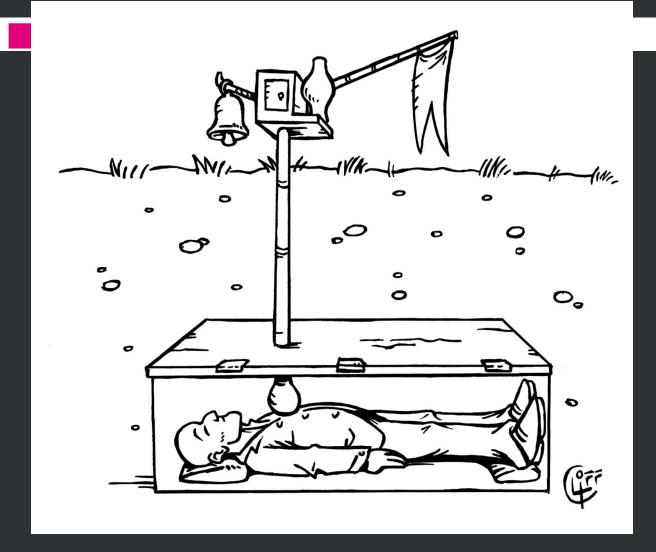


Blue = hypometabolic areas

Charland-Verville and al., Cortex, 2013



## "I am **not** dead "



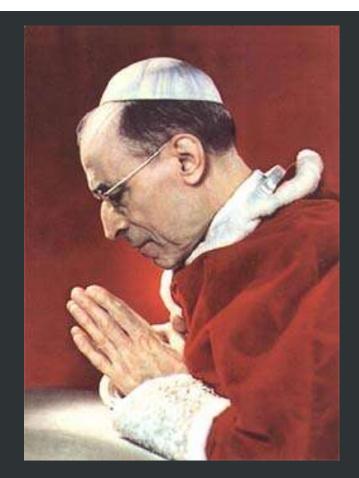


# Brief history of death

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Bjørn Ibsen – Copenhagen 1952



Pius XII – Vatican 1957

# Clinical death ≠ death



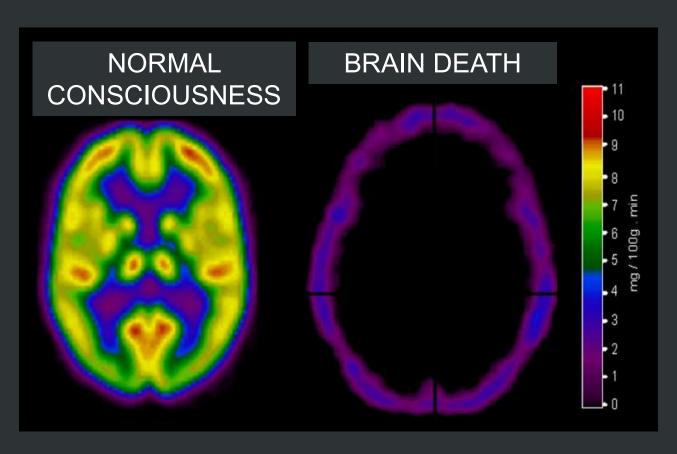
Transplants - Are the donors really dead ?

Since the 50's, no one with the criterias of brain death ever recovered consciousness



#### Brain death = death

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The hollow-skull sign



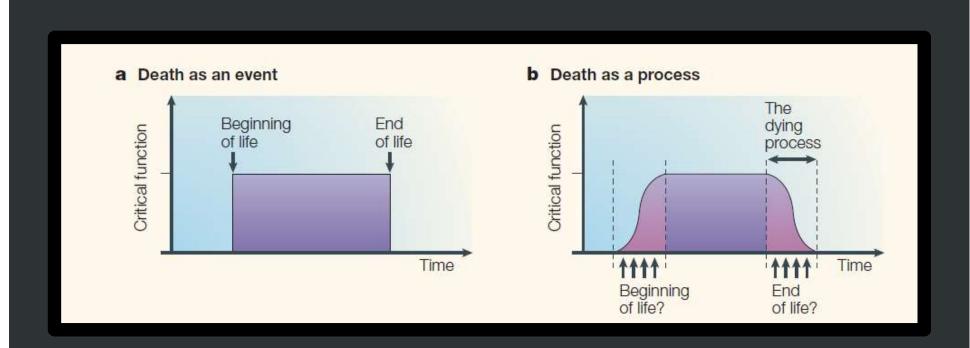
#### 8 criteria's of brain death

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- Demonstration of coma
- Evidence for the cause of coma
- Absence of brainstem reflexes
- Absence of motor responses
- Apnea
- Absence of confounding factors,
- A repeat evaluation after 6 h is advised
- Confirmatory laboratory tests are only required when specific components of the clinical tests cannot be reliably evaluated



## Death: event or process?



#### Death donor rule

- Patient must be declared dead before any organ removal
  - No matter the state of the person
  - No matter how much good it could do

Even if there is a lack of donors ...

Depends on the definition of death ...

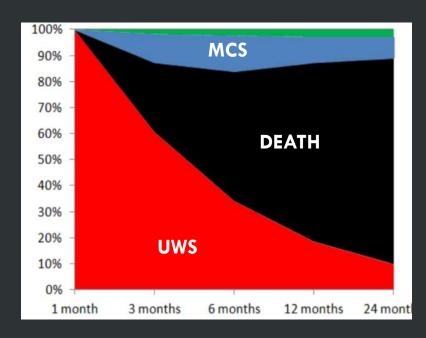


#### Neocortical death myth

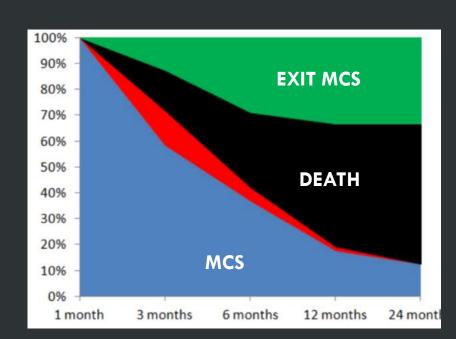
Death = permanent cessation of "higher functions of the nervous system that demarcate man from the lower primates"

- → Could include UWS patients as well as MCS patients!
- Incomplete understanding of consciousness
- 2. Clinical tests would require the provision of bedside behavioural evidence
- 3.Complimentary tests for neocortical death
- 4. Proving irreversibility is key to any concept of death

First diagnosed as Unresponsive Wakefulness Syndrome (UWS)



First diagnosed as
Minimally Conscious State
(MCS)



Cassol et al, in preparation



# 3. Unresponsive Wakefulness Syndrome



#### UWS ≠ brain dead

Coma 

No eye opening

Reflex behaviour

WCS

Eye opening

Eye opening

Non reflex behaviour

- UWS: wakefulness with no signs of awareness
- Both terms are all often mixed up in the lay and even medical — press.
- Payne & al. (1996) showed that ...

US neurologists and nursing home directors believed that UWS patients could be declared dead!

Laureys, Nature Reviews Neuroscience, 2005; Payne and al., Ann.Intern.Med., 1996



# The case of Terri Schiavo





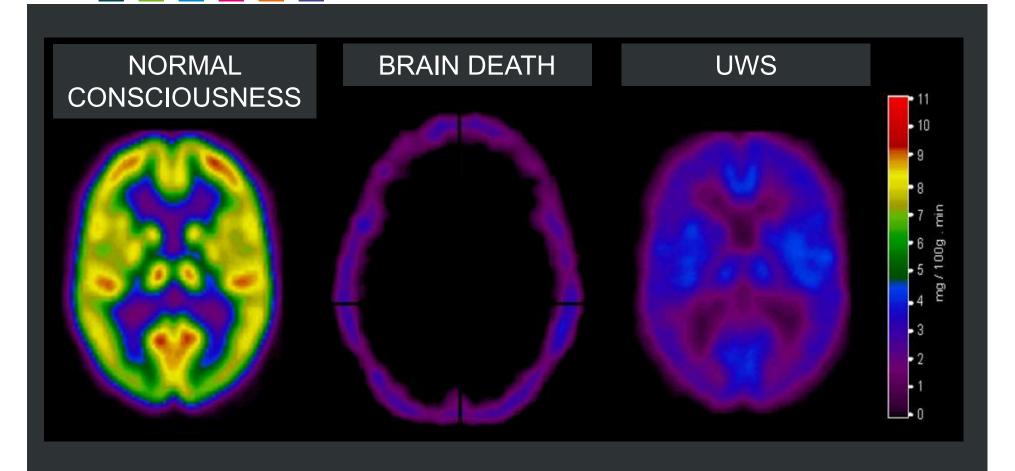


# Clinical & diagnostic differences

	Diagnosis	Eye opening	Breathing	Brainstem reflexes	Movements
Brain Death	Within hours / days	No	With assistance	Altered	Generated by residual spinal activity
Irreversible UWS	3 Month (NTBI) 12 Month (TBI)	Spontaneously open	Spontaneously without assistance	Preserved	Much richer array of motor activity

#### Brain metabolism

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#### "More dead than dead?"

- Dualism in consciousness : mind OR body / mind AND body ?
- Being in a persistent UWS < being dead</li>
  - For themselves
  - For a family member
- Perception of mind as a persistent UWS < being dead</li>
  - Persistent UWS are considered as a body > as a mind
- Alterlife beliefs and high reliogisity +++
- Being in a persistent UWS = less than dead

1d

PERSISTENT VEGETATIVE STATE

Demertzi and al., Ann. N.Y. Acad. Sci, 2009; Kurt and al., Cognition, 2011



# 4. Ethics of death and dying





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#### Clinical context (1)

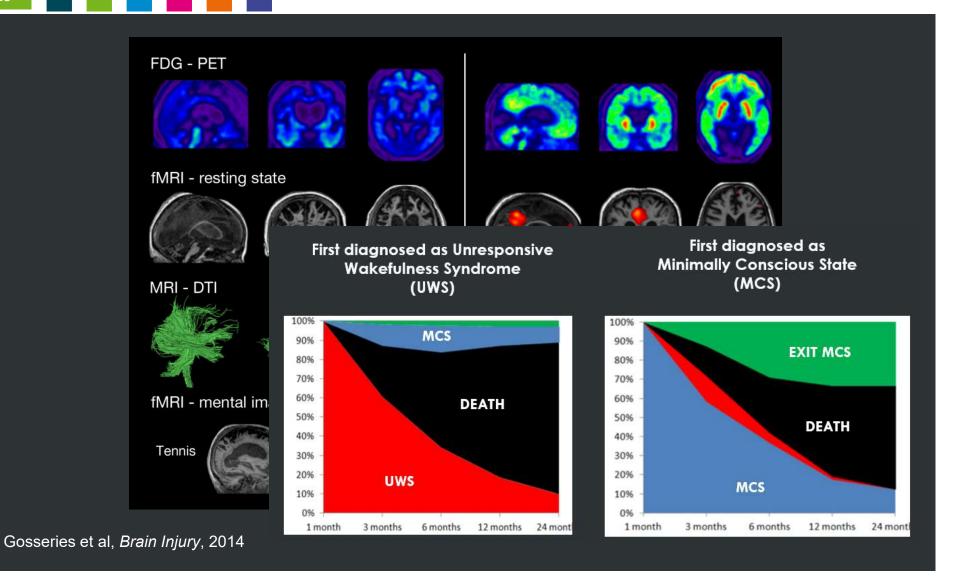
JFK COMA RECOVERY SCALE - REVISED 82004 Record Form Patient: Date: **AUDITORY FUNCTION SCALE** 4 - Consistent Movement to Command \* 3 - Reproducible Movement to Command \* 2 - Localization to Sound 1 - Auditory Startle 0 - None VISUAL FUNCTION SCALE 5 - Object Recognition \* 4 - Object Localization: Reaching \* 3 - Visual Pursuit \* 2 - Fixation \* OROMOTOR/VERBAL FUNCTION SCALE 1 - Visual Startle 3 - Intelligible Verbalization \* 0 - None MOTOR FUNCTION SCALE 2 - Vocalization/Oral Movement 6 - Functional Object Use 1 1 - Oral Reflexive Movement 5 - Automatic Motor Response \* 0 - None 4 - Object Manipulation \* COMMUNICATION SCALE 3 - Localization to Noxious Stimulation \* 2 - Functional: Accurate 1 2 - Flexion Withdrawal 1 - Non-Functional: Intentional \* 1 - Abnormal Posturing 0 - None/Flaccid 0 - None AROUSAL SCALE The Coma Recovery Scale 3 - Attention 2 - Eye Opening w/o Stimulation 1 - Eye Opening with Stimulation 0 - Unarousable **TOTAL SCORE** 



Wannez et al, Ann Neurol., 2017; Stender & Gosseries et al, Lancet., 2014

# Clinical Misdiagnosis

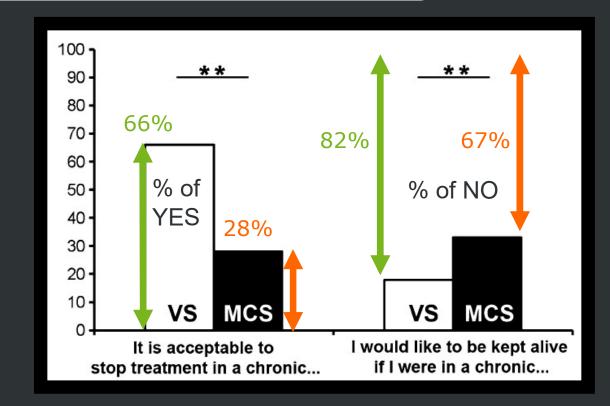
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#### Ethical implications

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Attitudes towards end-of-life issues in disorders of consciousness: a European survey

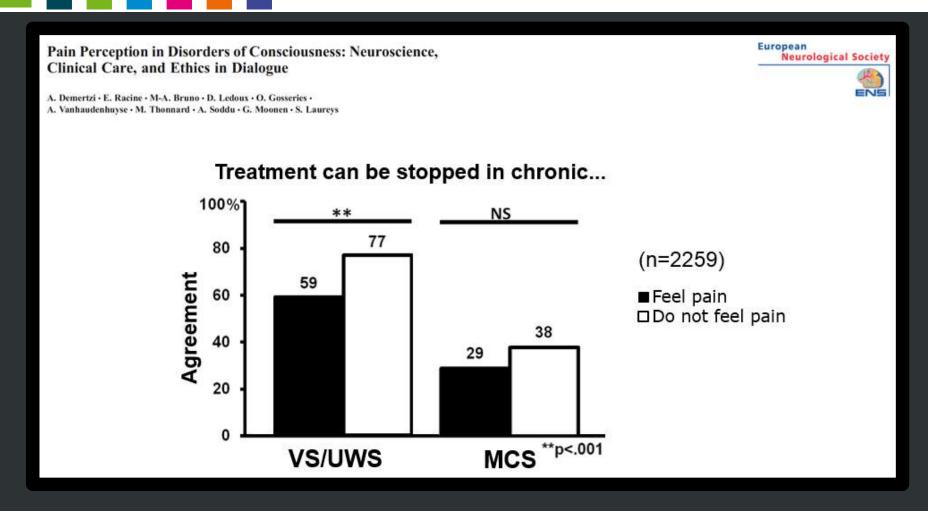


Demertzi and al., J Neurology 2011; Gipson and al., Neuroethics, 2014



#### Attitudes towards pain & end-of-life

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Demertzi & Racine and al., Neuroethics 2012



# Proxy decision-makers (PDM)

Generally family members

High psychological distress

Great physical and cognitive demands

Struggling with the uncertainty and the grief





### Theoritically, how?

The way the PDM should act on behalf of the patient is a progressive one:

Wishes of the patient

2. Patients' preferences based on their history and personal values

3. Objective markers that determine the patients' best interest



#### Reasons to overrule patient wishes (1)

#### The expected recovery of the patient

- 1. Realists that understand the gravity of the situation and know that prolonged care for a patient in a UWS would be futile
- 2. Procrastinators who were unsure or have heard of unexpected recoveries
- 3. Fighters who were willing to sacrifice themselves for the patient and put trust in a miraculous recovery
- 4. Family caregivers being ambivalent between hope, anticipatory grief and acceptance of the condition



#### Reasons to overrule patient wishes (2)

□ The family definition of life sustaining treatment

➤ Artificial Nutrition and Hydration ≠ medical intervention

□ Moral obligation to not cause harm or pain

Fear of letting the patient starve to death



# Influencing factors

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Personal characteristics and life circumstances

Social network and interactions

Communication and relationship with the clinician

Relationship with patient



#### PDM's and the healthcare providers

Limited contact and discussions

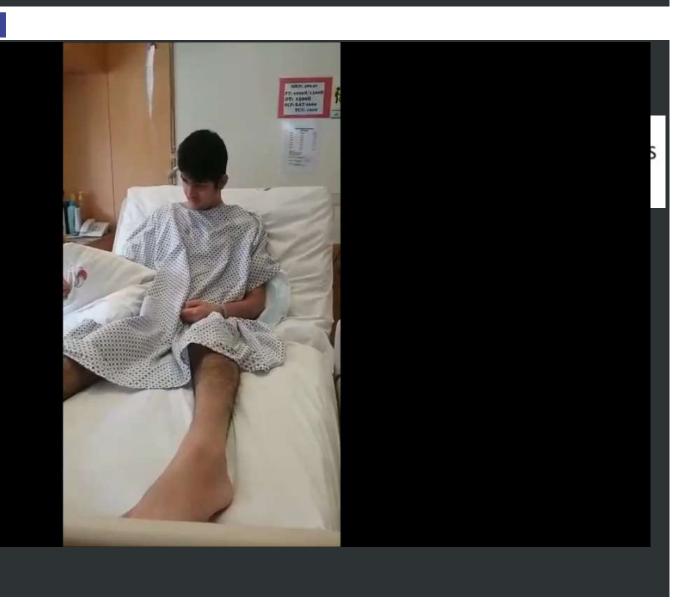


- Quality of interaction suboptimal:
  - Vocabulary used: interfere with the understanding of info
  - Not enough emotional support
- Shared decision making > satisfaction from families
- Open communication even if uncertainty about the prognosis



# What about Exit MCS patient?

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# 5. Near Death Experience

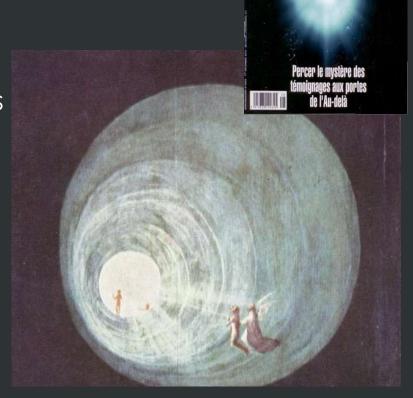




#### "I was **almost** dead"

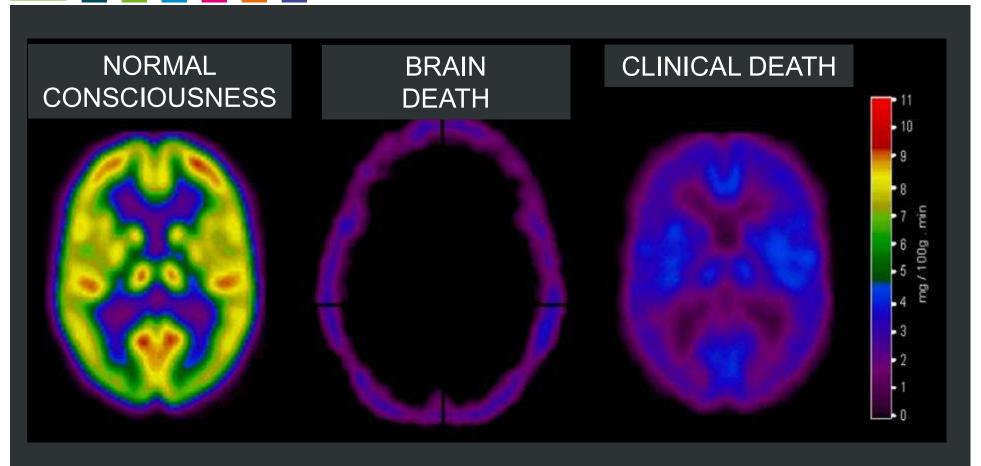
Set of mental events

- Rich emotionnaly
- Spiritual and mystic characteristics
- Perceived or real dangerous physical or emotional situations
- Realistic Intensity
- Common characteristics
- Altered or Modified States of Consciousness





#### Brain death ≠ clinical death



Towards a neuro-scientific explanation of Near-Death Experiences?



#### NDEs and Science

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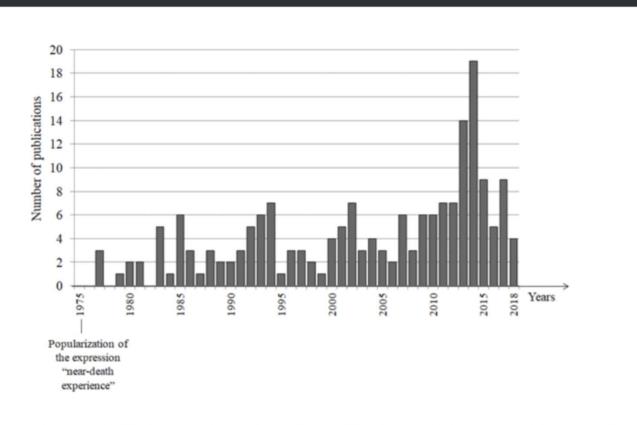
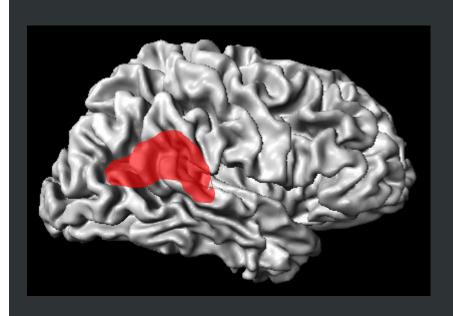


Figure 4 – Number of publications per year on NDEs (for a total of 185 publications). Medline search performed in February 2018 with the keyword "near-death experiences".



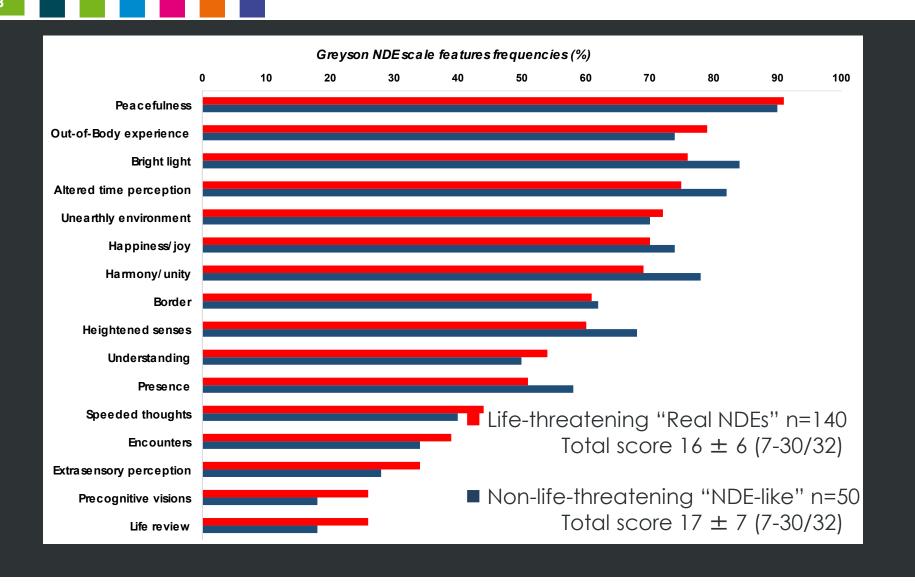
# «I left my body»

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Blanke et al Stimulating illusory own-body perceptions. *Nature*, 2002 De Ridder et al Visualizing out-of-body experience in the brain. *N Engl J Med*, 2007





# 6. Conclusion



#### Take home message

- Different altered states of consciousness
- DEATH = BRAIN DEATH ≠ UWS
- Ethical issues
  - Diagnostic accuracy
  - End of Life decisions
- Making & promoting advance directives = help respect patient wishes
- Only proof of life after death is organ donation!

If you want more informations, contact: <a href="mailto:awolff@uliege.be">awolff@uliege.be</a>

# Thank you for your attention!















You lived a « near death experience » and want to testify?

Contact us!

hcassol@uliege.be



