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- The demand for certainty is one which is natural to man, but is nevertheless an intellectual vice

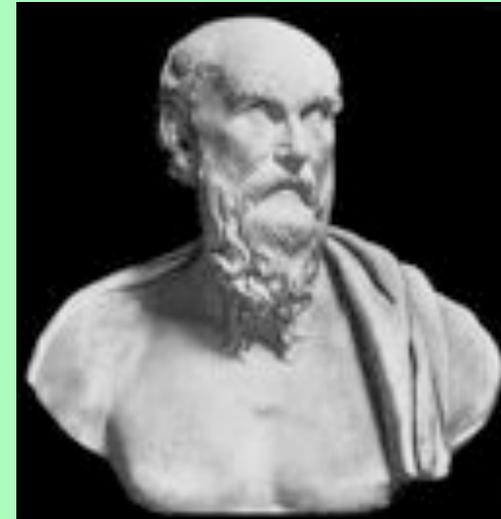
Bertrand Russell



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- *How to find unity in diversity, and how to find a permanent principle in the midst of flux*



the Humanities

We are born copies....



...but die as originals

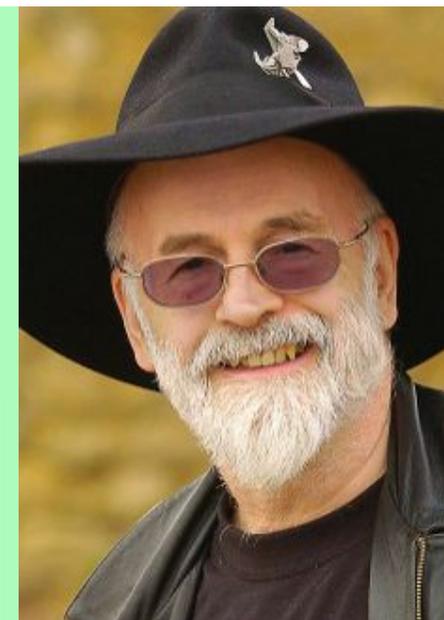




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VIEWS & REVIEWS

TELEVISION REVIEW

We are not alone

What pressures does assisted dying place on loved ones? A programme in which Terry Pratchett sees a man take his own life stirs feelings in **Desmond O'Neill**

Terry Pratchett: Choosing to Die

First shown on BBC2 on 13 June 2011

www.bbc.co.uk/programmes/b0120dpx

Rating: ***✪

One of the most insightful passages in Joseph Conrad's *Heart of Darkness* occurs at the beginning of the novel as they cruise down the Thames, when the narrator outlines what really captivates in a narrative. To him "the meaning of an episode was not inside like a kernel but outside, enveloping the tale which brought it out only as a glow brings out a haze, in the likeness of one of these misty halos that sometimes are made visible by the spectral illumination of moonshine."

I was reminded of this while watching the Terry Pratchett programme on assisted dying. In this documentary, the *Discworld* author, who was diagnosed as having Alzheimer's disease in 2008, travels to the Dignitas clinic in

personal assistant, we got a strong sense of the demands that assisted suicide places on those dear to people who choose, or are thinking of choosing, this form of death.

It is these witnesses who add an extra dimension to the debate about coercion and assisted suicide. Usually this concern focuses on the person who is the subject of the death, but a broader view helps us to see how others might also find themselves emotionally pressured. If a strong-willed person decides to take this route it could place a parent, adult, child, or partner in a difficult position, neither truly wishing for the death nor feeling it possible to let it happen unaccompanied.

It is a huge burden to bear, and parental, spousal, or filial loyalty may make it a challenge not to find your emotional and moral compass twisted. Not

reflections on how decent and caring physicians get involved in the death penalty (*N Engl J Med* 2006;354:1221-9). This article should be a catalyst for the development of an ethical and emotional articulation to protect us (and those we care for) from such pressures, an articulation that is not always easy to display in our bluff, practical, and often utilitarian style of medical discourse.

And indeed, we might be supported in this by a positive, if unintended, insight into the meaning of life with disability, which was again "outside of the kernel" of the intended narrative of this largely polemical documentary. It was impossible not to be struck by how the supportive relationship between Rob and Terry shone through as an example of adaptation to progressive neurological illness.

From the way that Rob supports him in his new way of writing, through dictation and feeding back the results (his new book, in a touch of possibly Pratchett-like irony, is called *Snuff*) to their evident pleasure in companionship and exploring new things, such as drinking wine together on the train as the snowy landscapes passed by, I was struck how easily we can forget that the warmth of relationships helps to keep our cognitive skills in

"Not wishing to be a burden" is in turn a different type of burden on those who care for and love us

Signe

SIGNÉ
PHILADELPHIA ONLY NEWS
PHOTOGRAPHY
USA

THE BEST SEAT for DECIDING the MORALITY of ASSISTED SUICIDE



PHOTOGRAPHY BY SIGNÉ PHILADELPHIA ONLY NEWS

I'M SORRY
BUT CONGRESS HAS
RULED THAT YOU'RE
NOT YET DEAD.

STAHLER.
©THE COLUMBUS DISPATCH
2005.



FAIRINGTON
3/5 06/11/05

THANKS FOR
THE LIFT.

THE
COURTS

SCHIAVO
CASE



Eric Baker
1944 - 1994





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Since, for the most part, students believe that they behave ethically, they are less likely to see the need for medical ethics education.

So, ... the first hurdle for professional schools ethics education is the establishment of its importance and its relevance

R Rhodes, 2002



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and the National Institutes of Health

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MedLine Ethics

Keeping the ‘medical’ in
medical ethics, and restoring
a sense of proportion to
ethical priorities



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- Upstream ethics
- Towards an ethics of care, communication and competence
- Emphasis on recognizing and supporting personhood in old age and dementia
- Developing articulacy and insight
- Personal and professional agency



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Upstream ethics

- Torture of prisoners
 - 383 papers
- Erosion of confidentiality among prisoners
 - 12 papers





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Which is the biggest ethical challenge?

- Inadequate opportunity for comprehensive assessment, treatment and palliation
- Right to die



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Code of practice

- Philosophy
- Habit
- Aesthetic



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Competence
Care
Communication
Reflective practice

Societal Contract
Ethics

Philosophy
Theology

Law





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What underpins?

- Judaeo-Christian
- Prejudices
- Human failings
 - Vested interests
 - Personal
 - Business



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How is my mother, doctor?

- Gynaecologist
- 43 year-old mother
- 19 year-old daughter



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How is my mother, doctor?

- **8%** did *not* wish for their families to be told about their diagnosis/assessment/
- **61%** wished for information to be disclosed to their families only *after* they themselves had received it
- Just **4.35%** of patients wanted their families to be given such information *before* they themselves received it
- **18%** reported that there was at least one person within the family to whom they did not want information disclosed to
- A total of **38%** objected to families receiving information via telephone



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Don't tell her she has dementia!

- Dementia disclosure
 - Don't tell my mother 83%
 - Tell me if I get it 71%

Maguire et al BMJ 1997



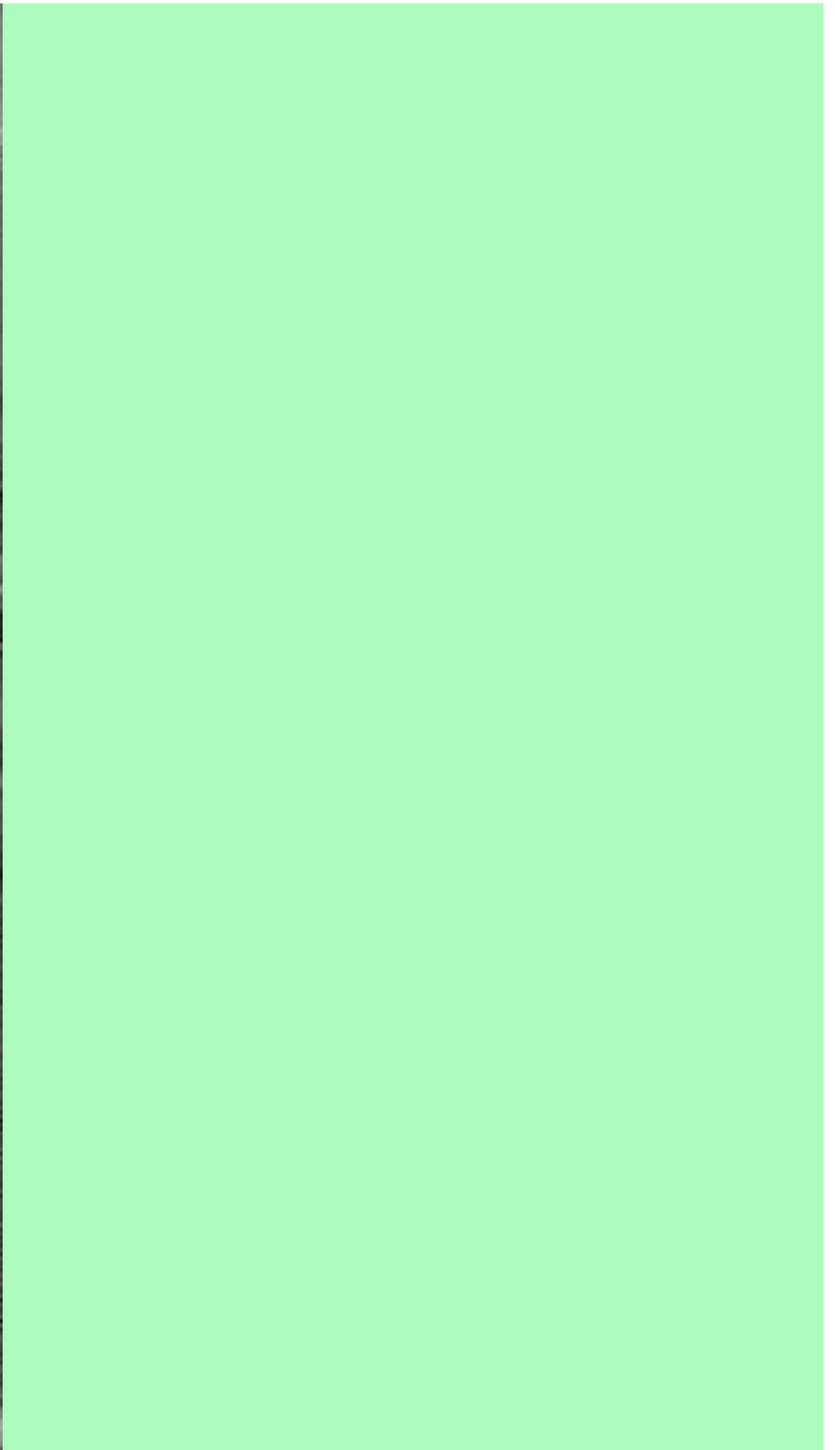
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Embracing complexity, avoiding

- Give me an algorithm
- Give me a law
- Artificial dichotomies
 - Autonomy/non-autonomy
 - Religious/non-religious ethical beliefs
 - Oral/PEG
 - Hospital bad/Nursing home good





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What processes do we bring?

- Longitudinal process
- Educational process
- Therapeutic process



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 EDITORIAL.

Editorials represent the opinions of the authors and THE JOURNAL and not those of the American Medical Association.

How Gravely Ill Becomes Dying

A Key to End-of-Life Care

Thomas E. Finucane, MD

noses and Preferences for Outcomes and Risks of Treatment), seriously ill patients estimated their chances of sur-

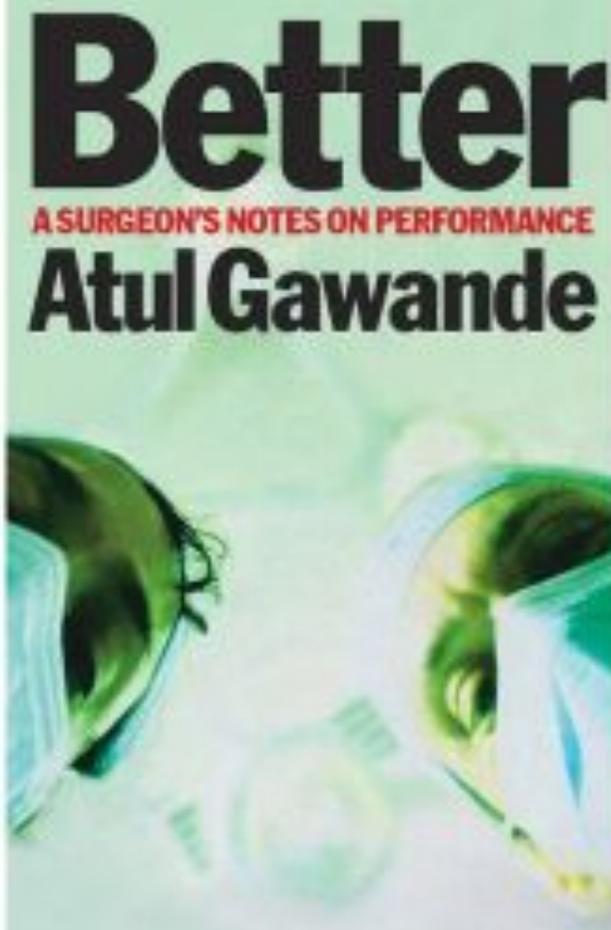


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Strategies



- Diligence
- Do the right thing
- Ingenuity



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Dementia and ethics

- Ageism
 - Patient, carers, professionals, state
- Perception of quality of life
 - Staff < Carer < Patient
- Cultural and generational expectations
- Compromised group
- Inadequate facilities
- Increasingly tax-averse culture
- Implied consent
 - Aspirin vs Thrombolysis



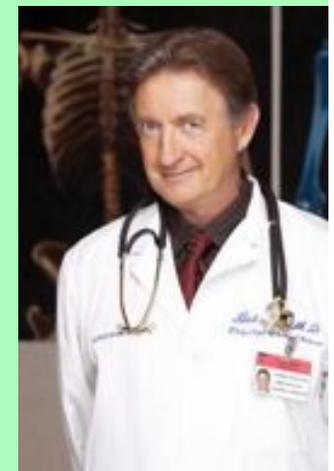
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Barriers

- Limitation of Beauchamp/Childress
 - Beneficence
 - Non-maleficence
 - Autonomy
 - Justice
- What doctors really do
 - Confidentiality, retained organs, public/private divide...

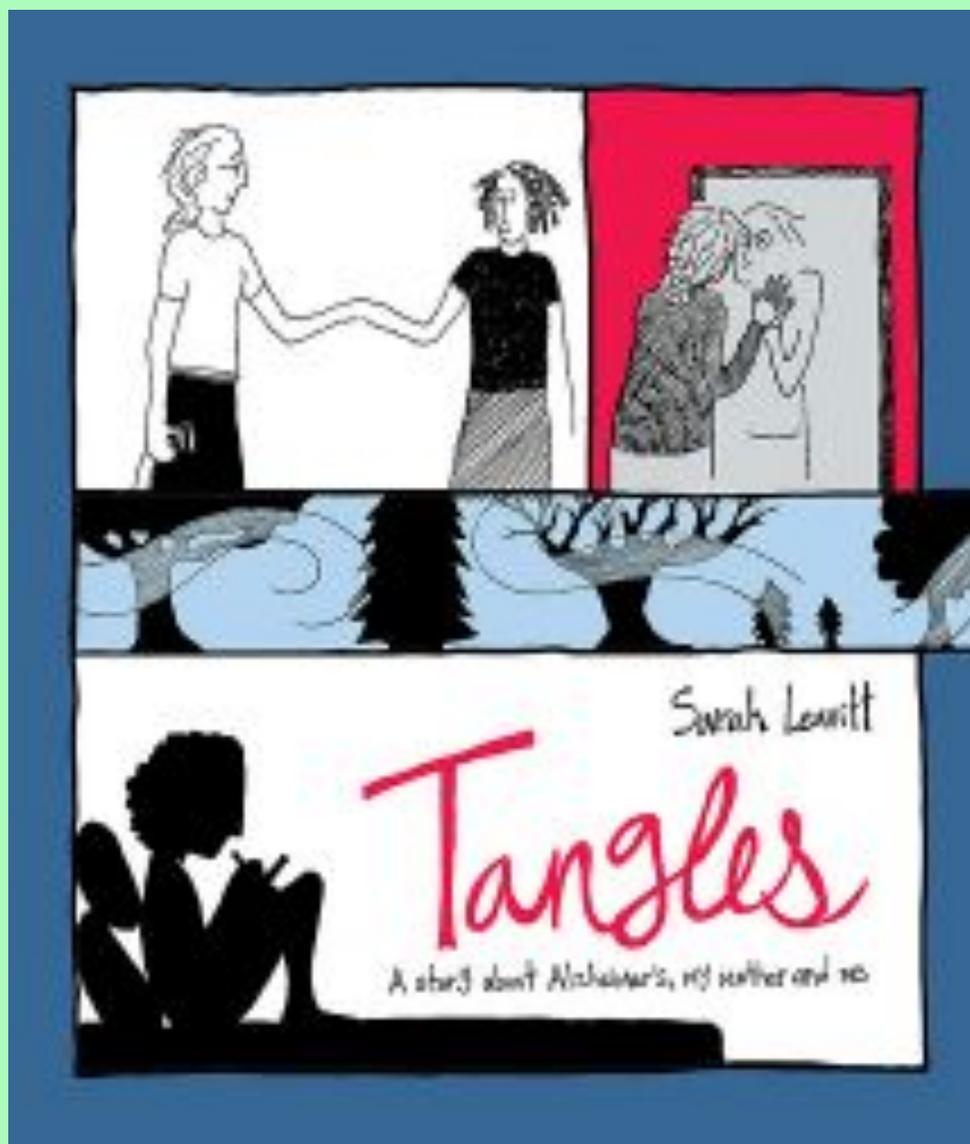




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Barriers

- Misapplication of autonomy
 - moderate autonomists, moderate welfarists
- Terminology
 - Dementia or
 - Major neurocognitive disorder?
- Negative nature of advance directives
 - Leslie Burke www.willtolive.co.uk/les_burke/main/
 - Don't put me in a nursing home



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Background

- UK - Utilitarianism
- Mainland Europe - Deontological
- US - Pragmatic philosophy



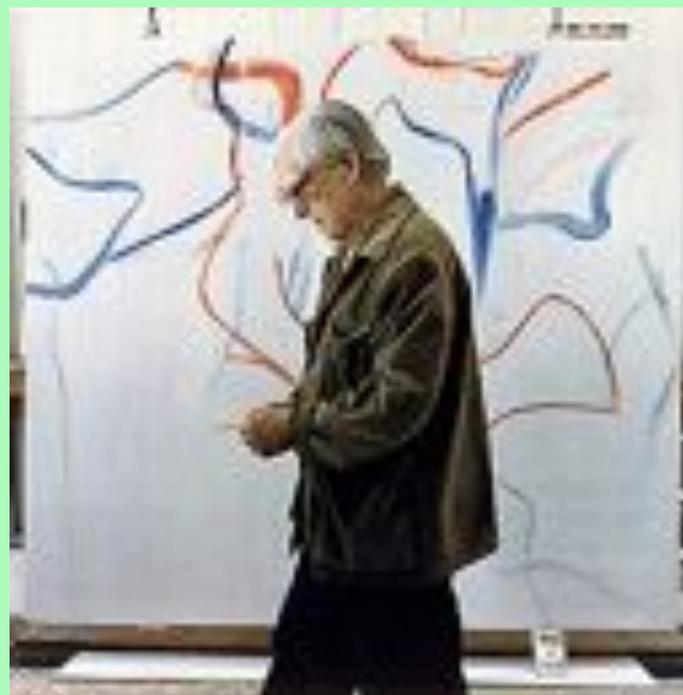
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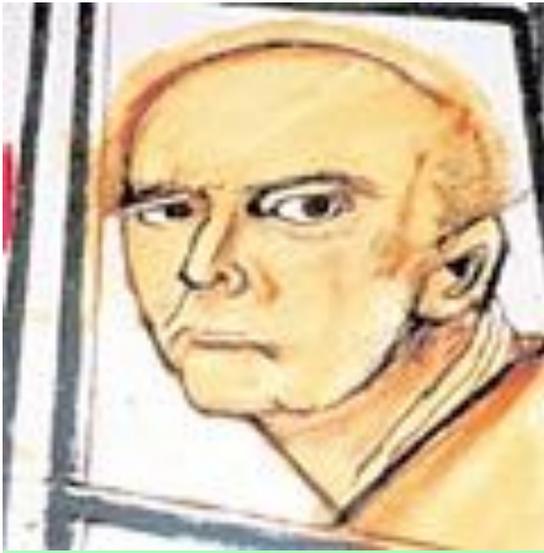
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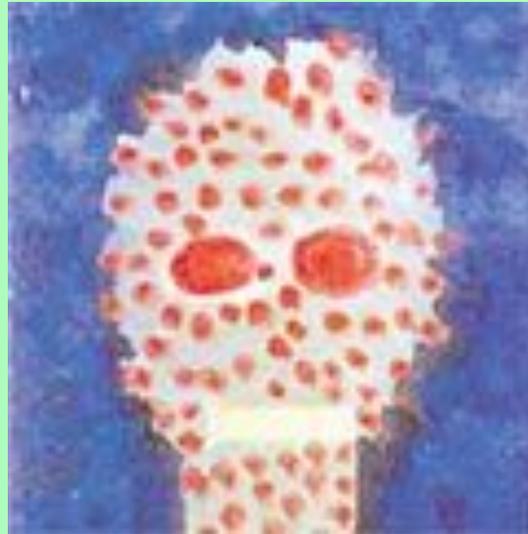
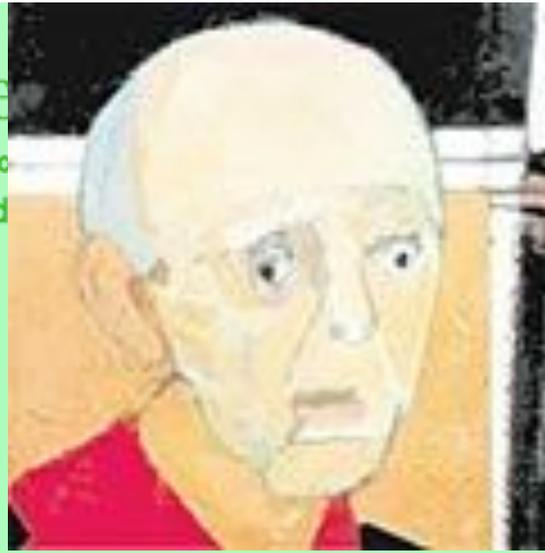
Contemporary issues

- Recognizing personhood in dementia





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The Man WITH A Shattered World



THE
HISTORY
OF A
BRAIN
WOUND

A. R. LURIA

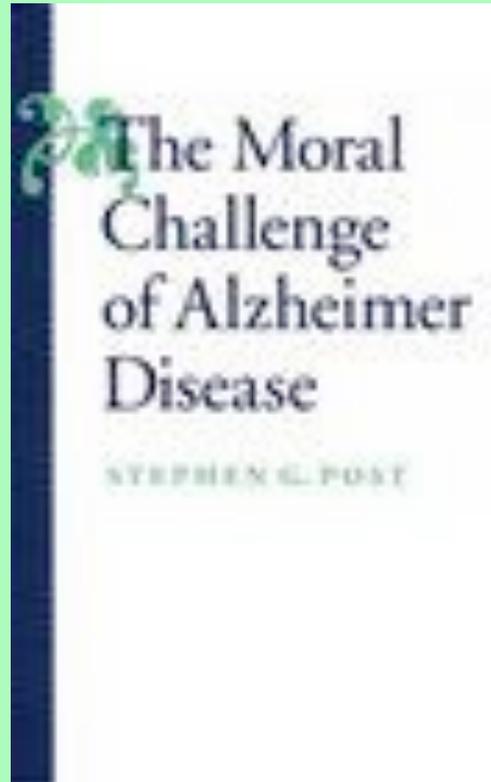
WITH A FOREWORD BY

Oliver Sacks

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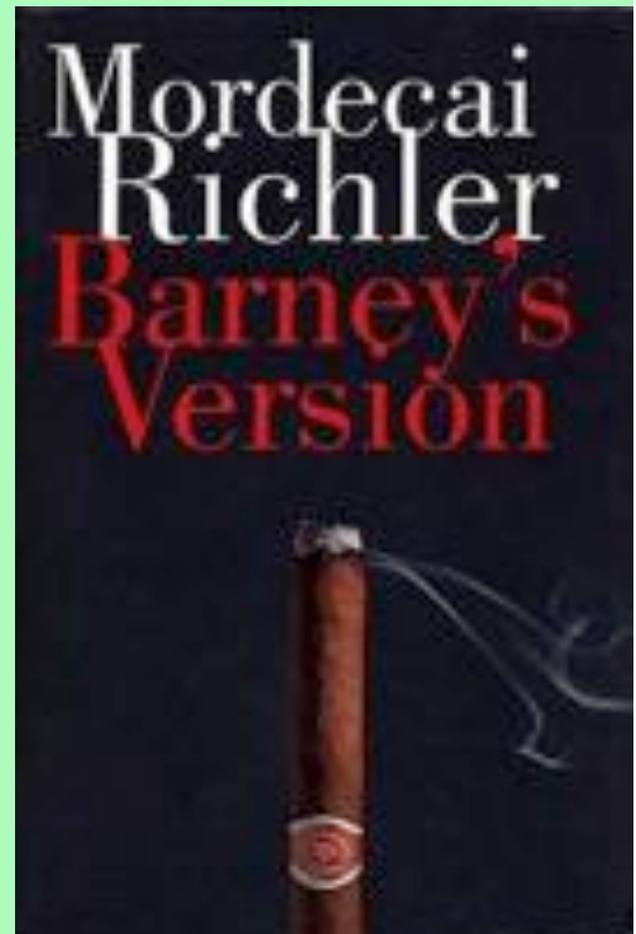
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The Moral
Challenge
of Alzheimer
Disease

STEPHEN G. POST



Mordecai
Richler
Barney's
Version

BMJ helping doctors make better decisions



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Ageing & Mental Health, March 2004; 8(2): 99–105

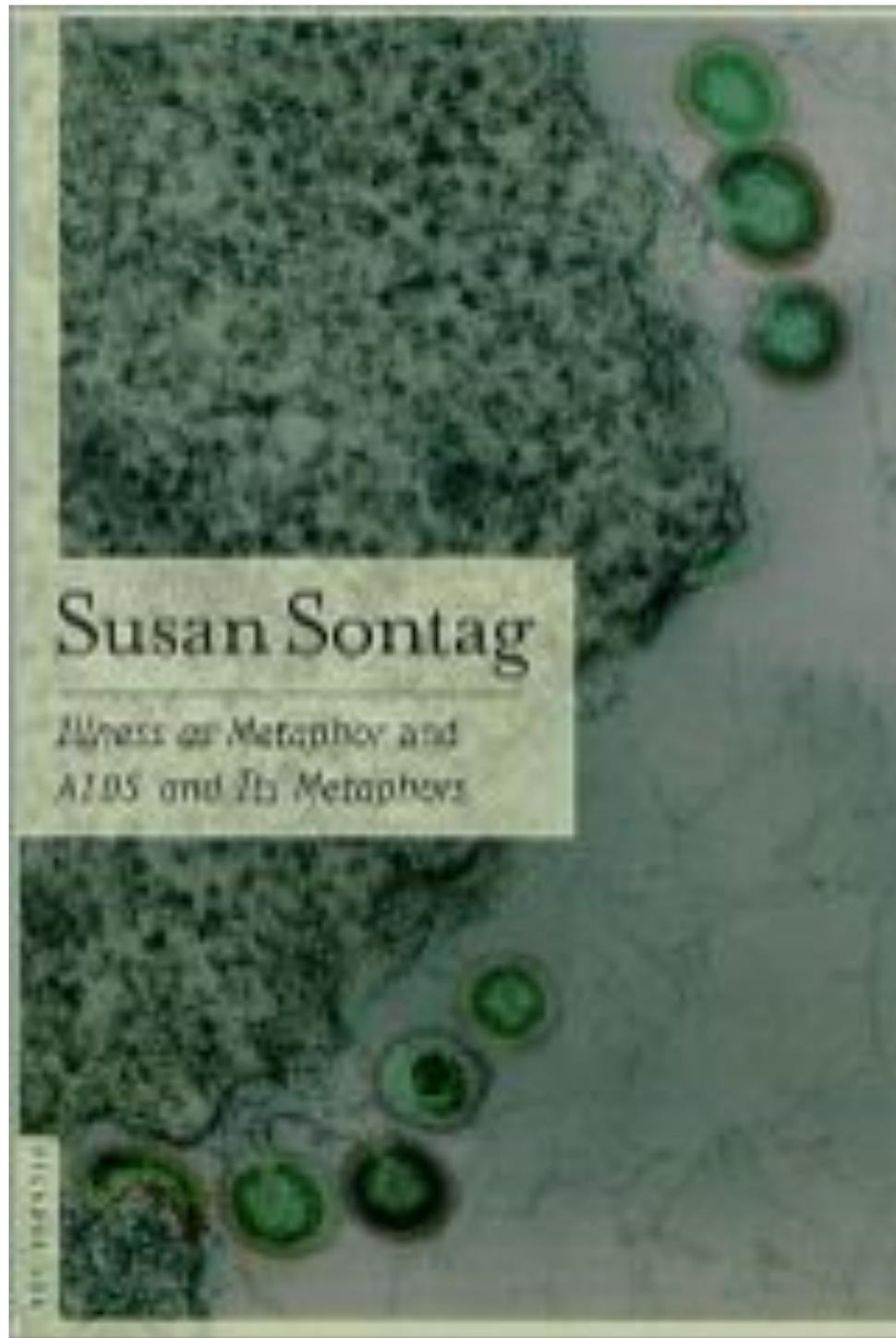
BrunnerRoutledge Taylor & Francis
healthsciences

EDITORIAL

The hazards of early recognition of dementia: a risk assessment

S. ILIFFE¹ & J. MANTHORPE²

¹Royal Free & UCL Medical School, London & ²King's College London, UK



Illness as metaphor

- Illness is the night-side of life, a more onerous citizenship...everyone holds dual citizenship
- Impossible to take up residence unprejudiced by the lurid metaphors with which it has been landscaped



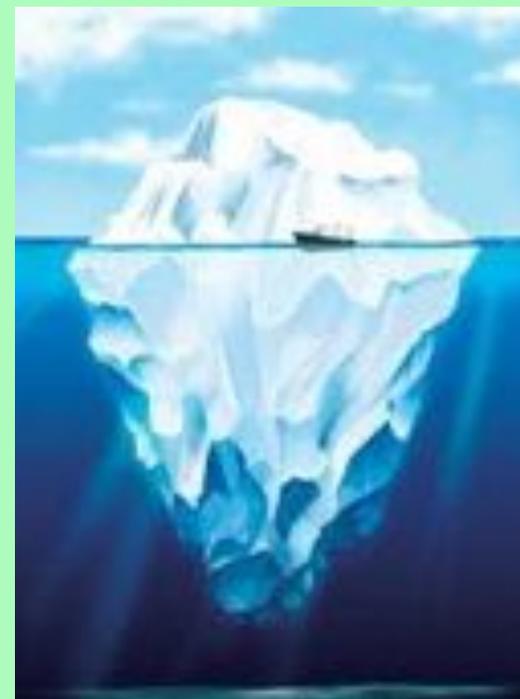
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2011 Research Criteria

- Pre-clinical AD
 - Amyloid/tau but nil clinically
- MCI due to AD
 - Amyloid/tau, memory loss, no dementia
- Dementia due to AD
 - Amyloid/tau, memory loss, dementia



NATIONAL INSTITUTES OF HEALTH

National Institute on Aging ■ ◆ ★ ✨

alz.org | alzheimer's association®



BMJ 2012;344:e3676



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Tom Regier



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Memory

- Clinic?
- Service?



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PEG feeding in post-stroke dementia

Should we insert a PEG in Mrs Smith, MMSE 10/30, who is no longer eating?



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Dementia assessment

- Maximize cognition and communication
- Comprehensive picture
 - Nursing****
- Clarify co-decision making dynamics
- Consider why Mrs Smith is not eating
- Review setting.....
- Clarify capacity



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Outcome - nutrition

- Good?
- Terminal care
- Self-determination
- Natural death



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Range of intervention

- Swallow therapy
- Altered consistencies
- Compensatory techniques
- Careful nutrition assessment
- Review of nursing-feeding practices



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MedLine

- from unknown unknowns to known unknowns
- no data to suggest that tube feeding can prevent aspiration pneumonia, prolong survival, reduce the risk of pressure sores or infections, improve function, or provide palliation
- some data to suggest that it does not

Finucane T, JAMA 1999 Oct 13;282(14):1365-70



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Terminus or gateway...

- Don't insert a PEG tube in dementia?
– or
- Better informed decision-making?



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Tips

- Low threshold for second opinion
- Write your thoughts down
- Remember your scope of practice
- Who is suffering - patient or carer?
- Look for unconscious rationing or perverse incentives
- Look at MedLine



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Profession

- Make case for adequate resource
- Deal with prejudice
- Self-critical
- Strive for evidence base
- Avoid narrow debate eg PEG vs no PEG
- Moral agency



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- In much wisdom is much suffering.. He that increases knowledge increases suffering

Ecclesiastes