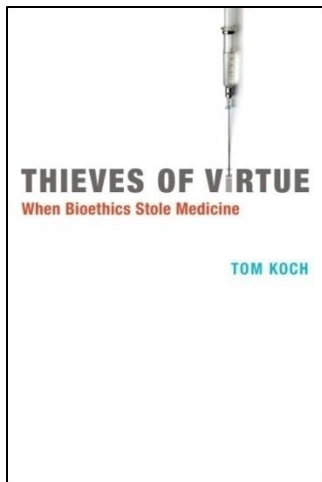
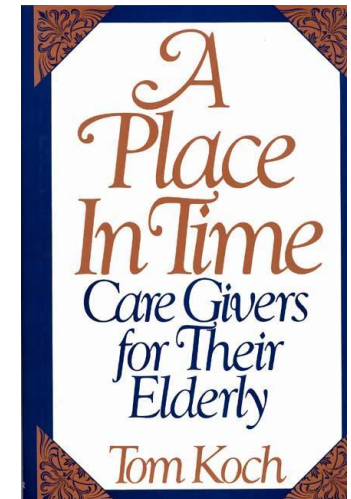
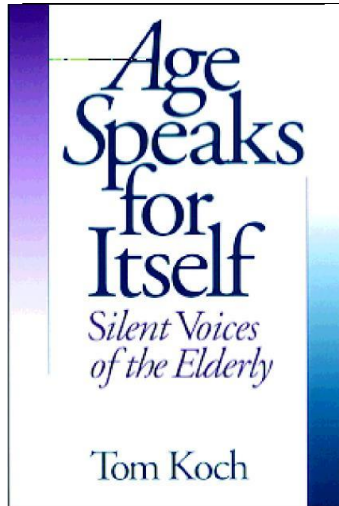


# Ethics and the care of patients with dementia: The carer's perspective.

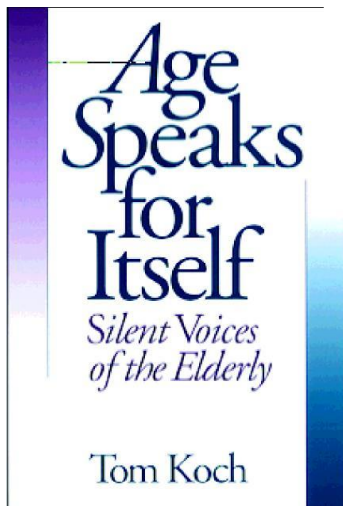
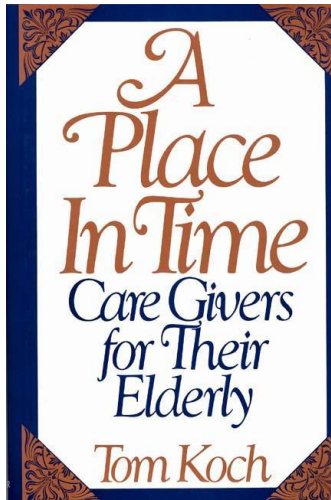


Tom Koch

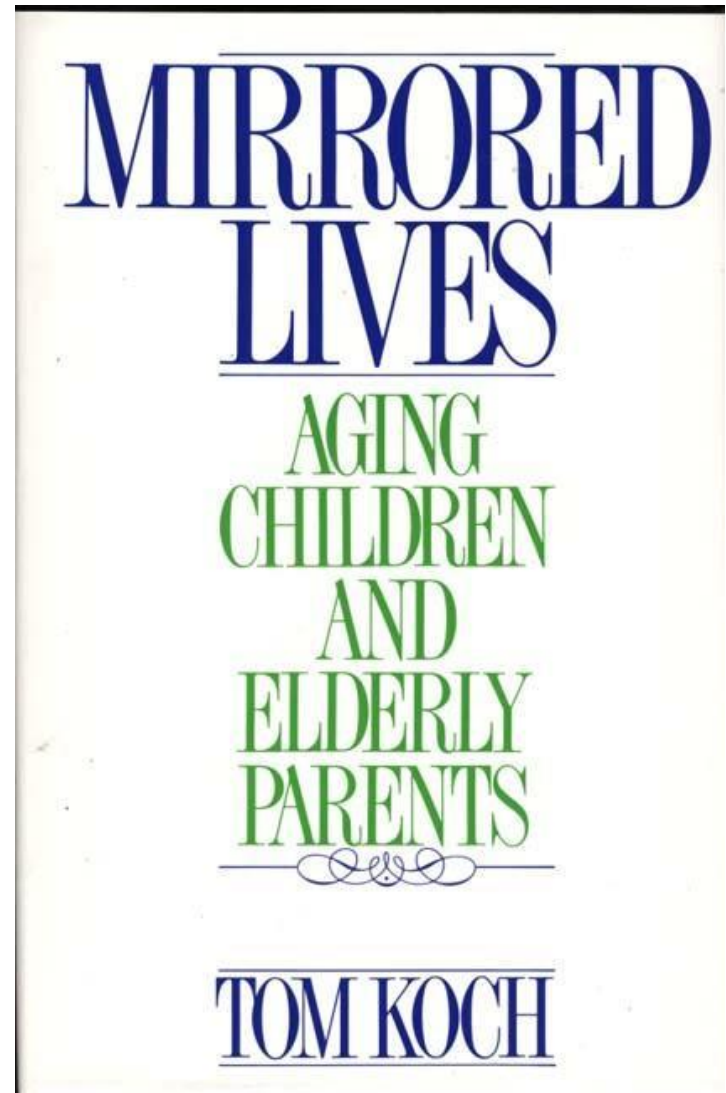
University of British Columbia,  
Vancouver, Canada.

Alton Medical Centre, Toronto Canada.

# A trilogy on care



*Mirrored Lives* (1990) was the first book to discuss the complexities of patient-based home care from the perspective of the patient and the carers.



# What do we know together we cannot express alone?



Doctors,  
nurses,  
patients,  
social  
workers,  
officials: We  
all face the  
same  
questions



Ethics is not just personal. It's also something shared.



# A few questions

- Questions: What care do we owe to all?
- Question: Does this include those with cognitive disorders?
- What happens when what I think is needed is denied by an employer?
- How do I handle disagreements within a family?
- Who is this person who doesn't recognize me, week by week, but whose care I provide?

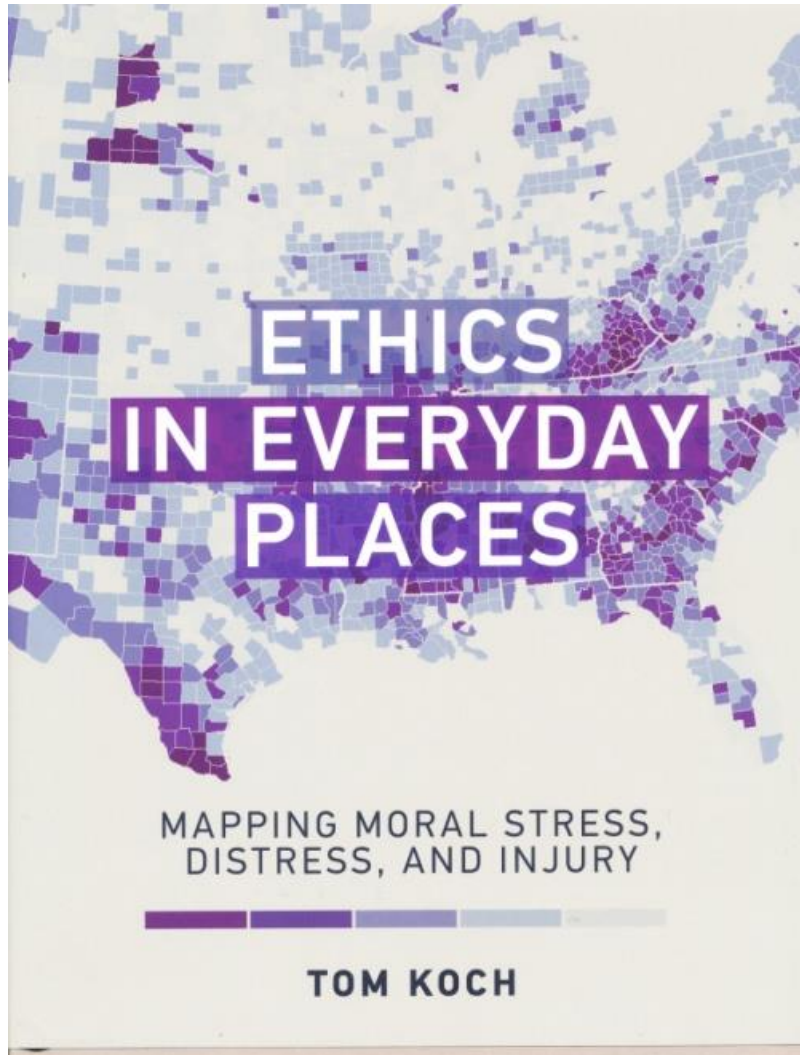
Alas, no  
magic wands!



Ethics gives some  
clarity that may  
lead to action, or  
change.



# Ethics as a daily activity.



Ideas about ethics and morals determine how we act in daily lives. They define the broad social acceptance or rejection of certain things. So they're real, and their effect on our work, and feeling about it, important to understand.

# Some Vocabulary: Ethics in Everyday Places

- *Ethics*: the code of behavior we live by, the way in which we separate right from wrong, good from bad.
- *Morals*: a small set of absolute values that our ethics serve to enact.
- *Justice*: The belief that our codes should apply equally to all.
- *Fairness*: Like justice, an idea that we all should be treated honestly and openly.



Ethics and  
morals are  
philosophy and  
philosophy is  
what we practice  
in the care of  
fragile others.

# BECOME Who You Are Practice Philosophy!



**Introductory workshop:**  
Monday November 16 @ 7:30pm  
Tickets / info :  
416-486-7198  
[Toronto.NewAcropolis.ca](http://Toronto.NewAcropolis.ca)

Jul  
Who You Are  
Introductory workshop :  
Monday November 16 @ 7:30pm  
215 Spadina Avenue, Alterna Room  
Toronto, NewAcropolis.ca  
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# Moral Stress, and Distress

- Moral stress arises when our ethical code argues one thing and others in authority insist on a different set of behaviors. It's called "moral stress" because, at root, it may reflect different principal values.
- When the different can not be resolved to everyone's satisfaction, a compromise, one is faced with distress...our code of behavior and our moral perspective are challenged.

# A Simple Moral statement

- Human life should be celebrated, nurtured, and preserved in its diversity. We are not disposable, fungible beings.



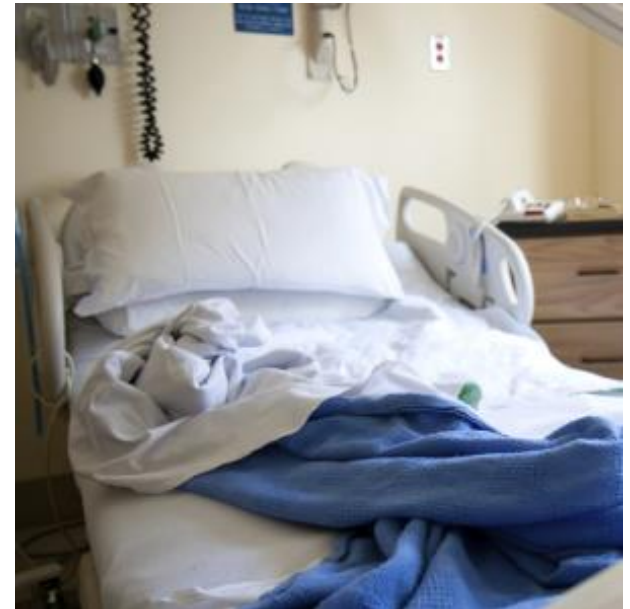
# Temporary problems or minor differences.



So what if you need a cane, or crutches, or a wheelchair for a time?

# Challenges Needing help

What about when the care needs are not temporary, but constant.



# Harriet McBride Johnson

McBride Johnson famously debated Princeton ethicist Peter Singer on the issue of differences and the need to see persons of difference as ... just persons.



**“We need to confront the life-killing stereotype that says we’re all about suffering. We need to bear witness to our pleasures.”**

**- Harriet McBryde Johnson**

# Down syndrome: An Example



Autonomy  
(independence)



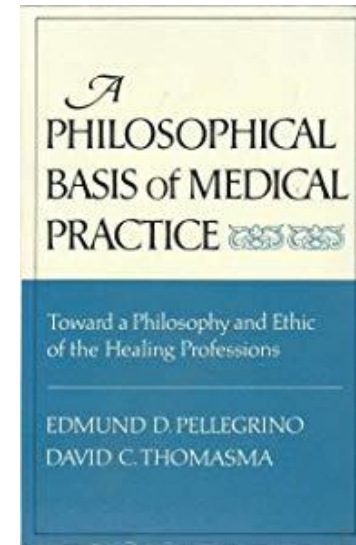
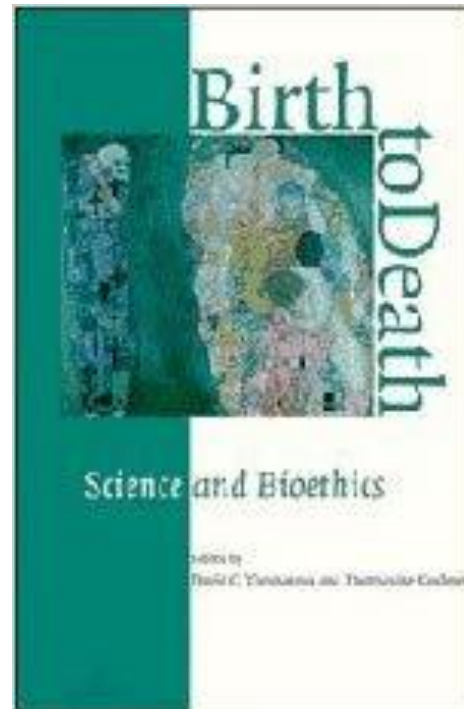
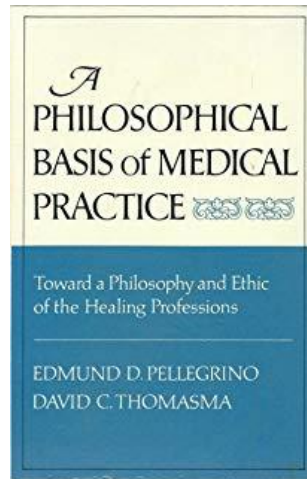


# Dementias

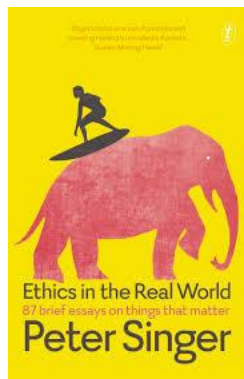
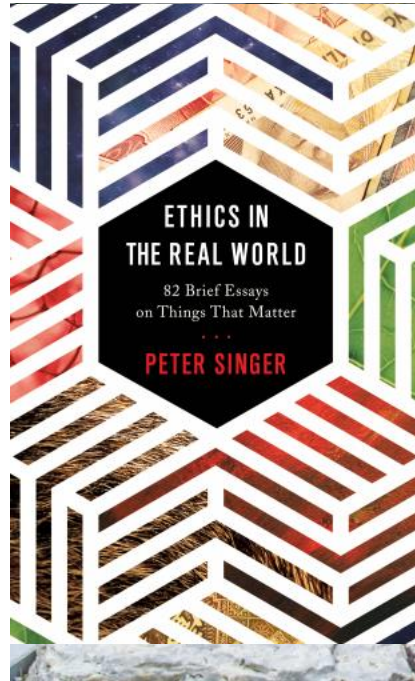


# Dave Thomasma: Personhood and difference

- Pre-person (unaware, but with potential)
- Person (Aware and autonomous)
- Post-person (no longer aware, no potential)

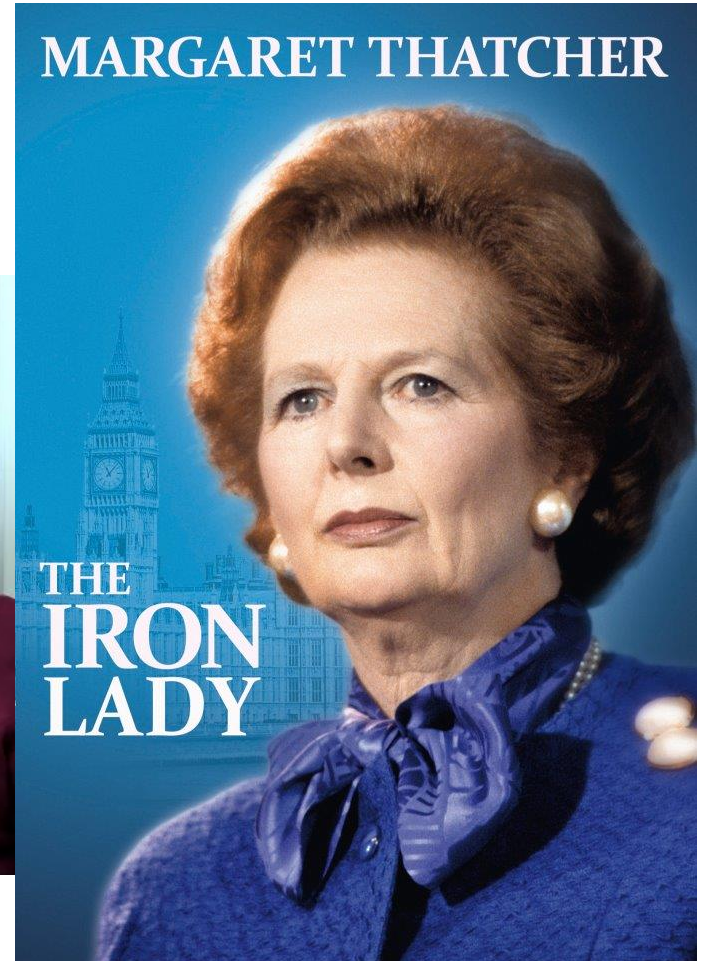


# Peter Singer and 'philosophy for the real world'



Is Peter Singer's world *our* world?

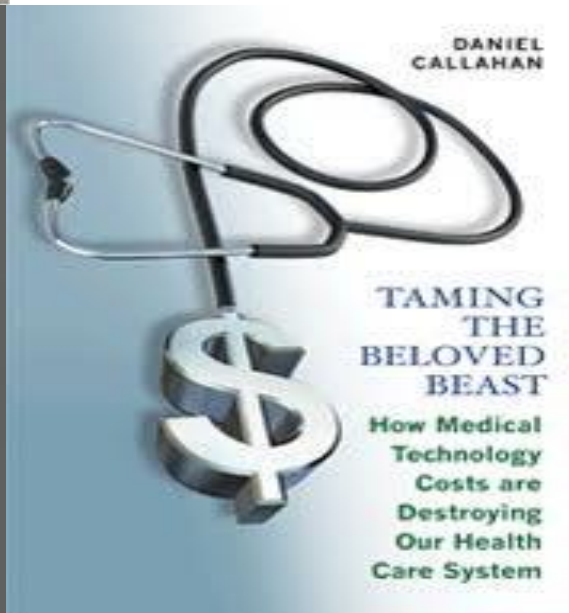
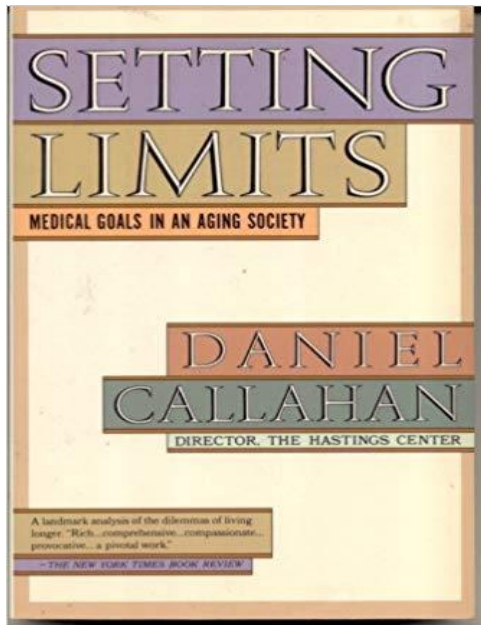
# Economics as the moral value



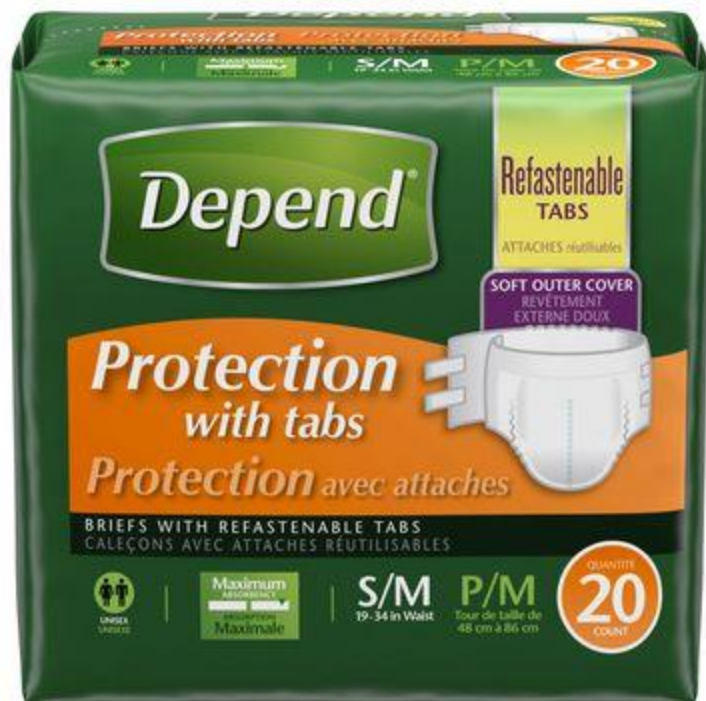
**Pre and early-dementia world leaders, the neoliberal champions.**

# Daniel Callahan And the economics of care

Society can't afford to care for everybody. So some, the elderly and the fragile, should be denied so that younger, more valuable folk can get the best care affordable.



# Incontinence is not worth dying for.



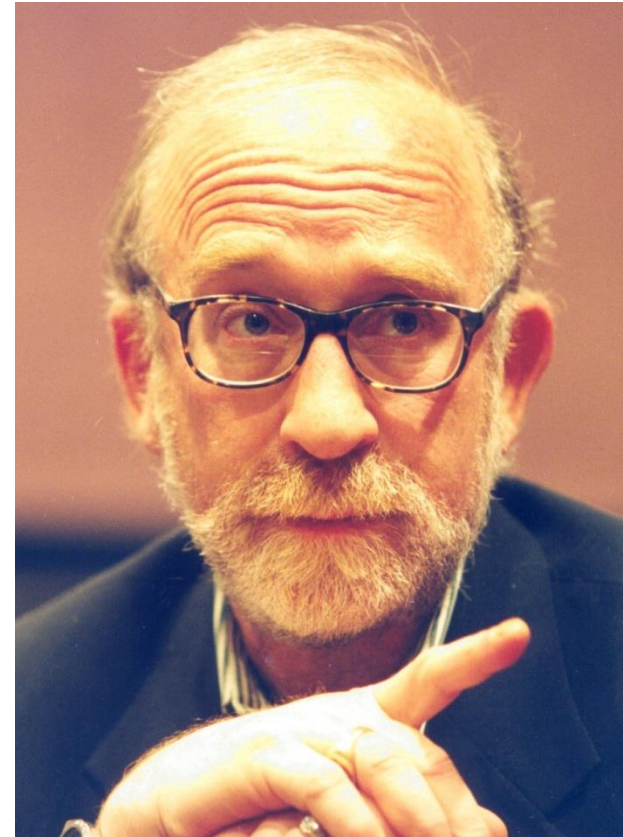
New sizes for a comfortable, tailored fit

# What about ...the money?



# Thank you

- My books and articles are listed on my webpage: <http://www.kochworks.com>
- My hope is that this talk will spark discussion, and questions about the real dilemmas that arise from your care of clients with dementia at home or in instructional settings.
- You can send further queries about your practice of care through the Alzheimer Society's Information Director, Mary Schultz: [MSchulz@alzheimer.ca](mailto:MSchulz@alzheimer.ca).





# Diversity and future persons.

