

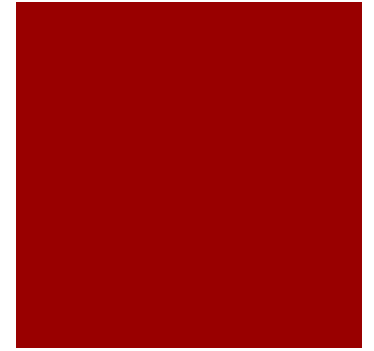
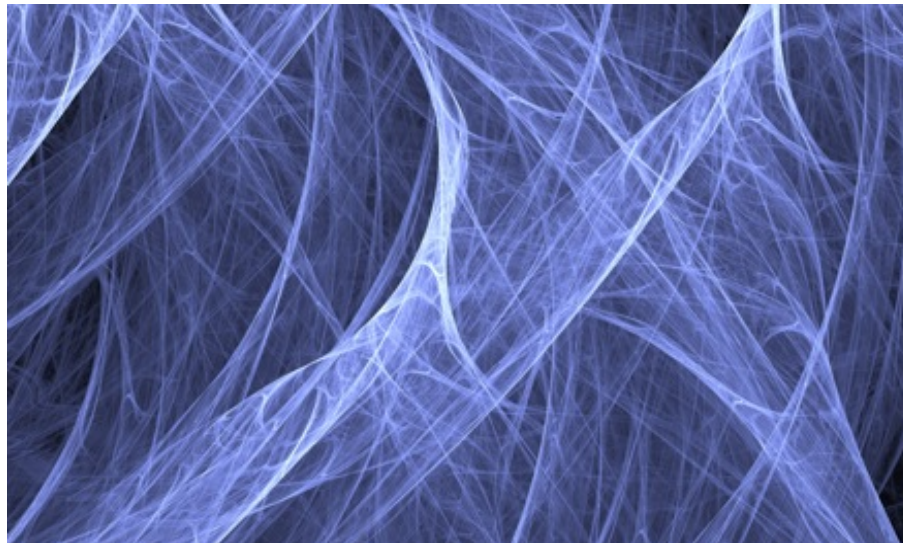


Hilde Lindemann
Michigan State University

Struggling to Catch Up: Families, Identities and Narrative Care

Personal Identities: A Web of Stories

- Acts
- Experiences
- Characteristics
- Roles
- Relationships
- Commitments



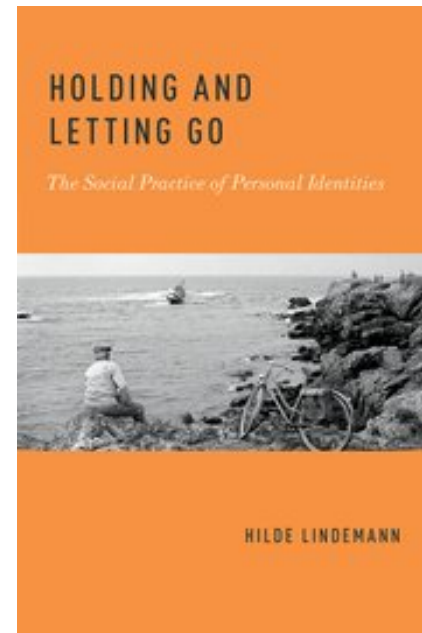
The Practice of Personhood

- Perform who we are
- Recognize others' performances of who they are
- Respond appropriately to these performances



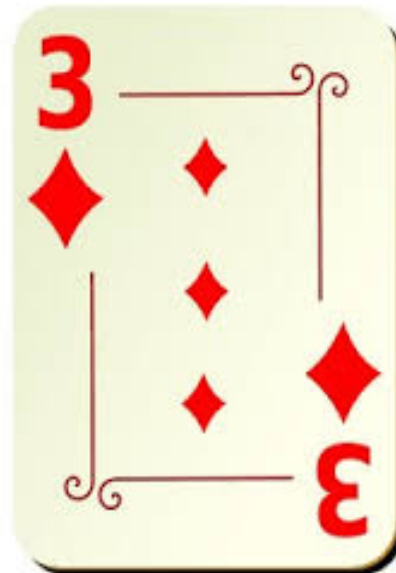
Holding and Letting Go

- Hold on to the stories that depict the person accurately
- Let go of stories that used to portray the person properly but no longer do



Three Cases

- Where the identity has changed radically
- Where the identity lies at the limits of responsibility
- Where the patient has lost her second nature

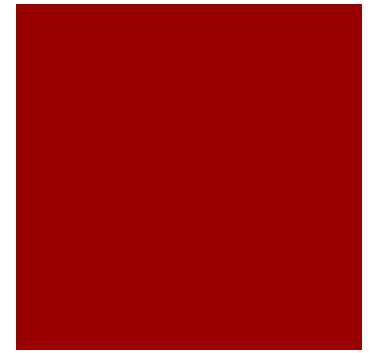


The Argument

- If health care professionals recognize and respect the familial labor of holding patients in their identities, they improve patient care.

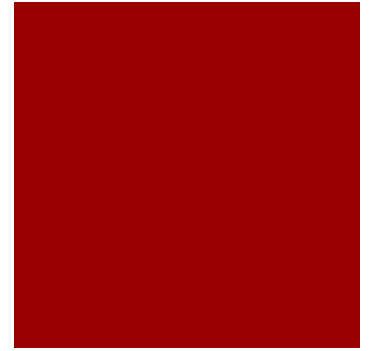


Radical Change



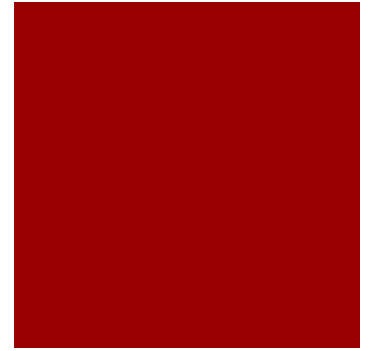
Second-Order Volition

- Endorsing or repudiating a desire
- Wanting (or not wanting) to want something



Wantons

- Act on their desires without reflecting whether they want to act on them
- Lack second-order volition



Changing Your Mind

- Repudiating what you used to endorse

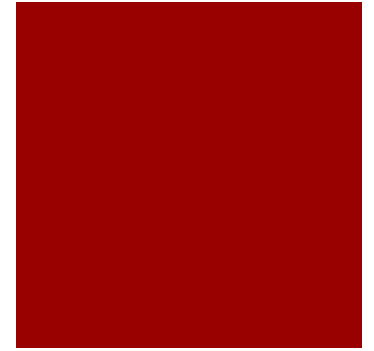


The Wife

- Helps her husband stay true to his lifelong commitments
- Holds him in his identity
- Possibly wants to keep him from complicity in evildoing



Identities at the Limits of Responsibility



- First, some theory: where do our responsibilities come from?

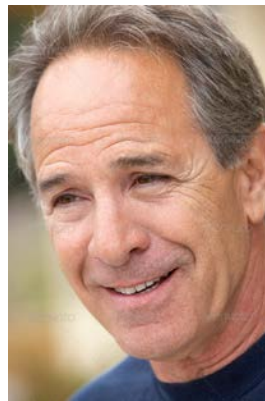
Philosophical Accounts

- “Easy rescue” (the beneficiary has everything to gain, the helper, nothing to lose)
- “Compensatory justice” (I have wronged someone and now owe her something to make it up to her, or have received benefits beyond my due and my acts ought to reflect that)
- Voluntary and informed consent (I promised to help or willingly assumed a certain social role)



But in Families?

- Responsibilities to my children: easy rescue?
- Responsibilities to my husband: compensation?
- Responsibilities to my sister: consent?

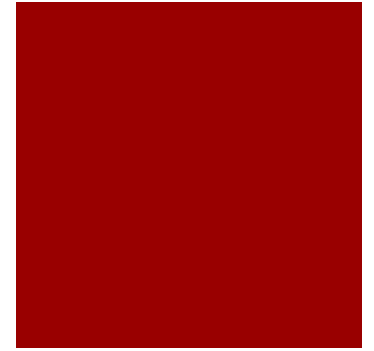


Ned and Sam



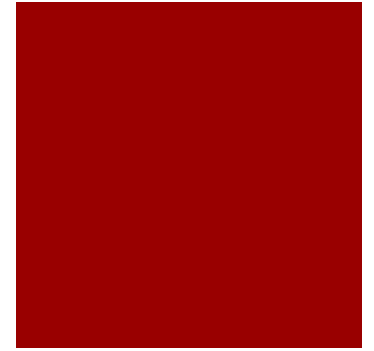
Sam's Brotherly Responsibilities

- To consider getting tested
- To recognize Ned as his brother



Justification

- Genetic ties are valued: isn't that what IVF is about?
- Responsibilities arise from genetic ties *and* shared history

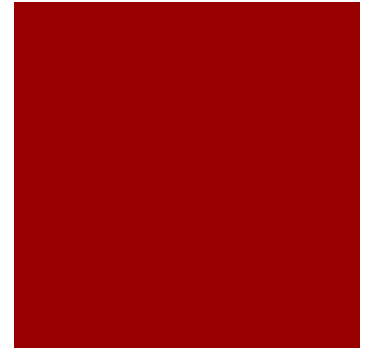


Second Nature



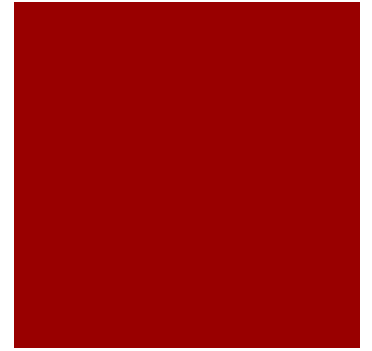
Second Nature

- Ability to use concepts
- Sense of what is ridiculous, ordinary, similar, different
- Sense of self and of who others are
- Ability to participate in the practice of personhood



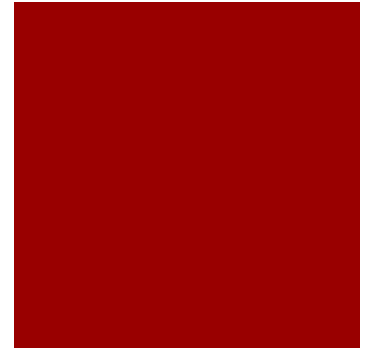
Holding in Personhood

- Preservative love: being kept safe from moral harm

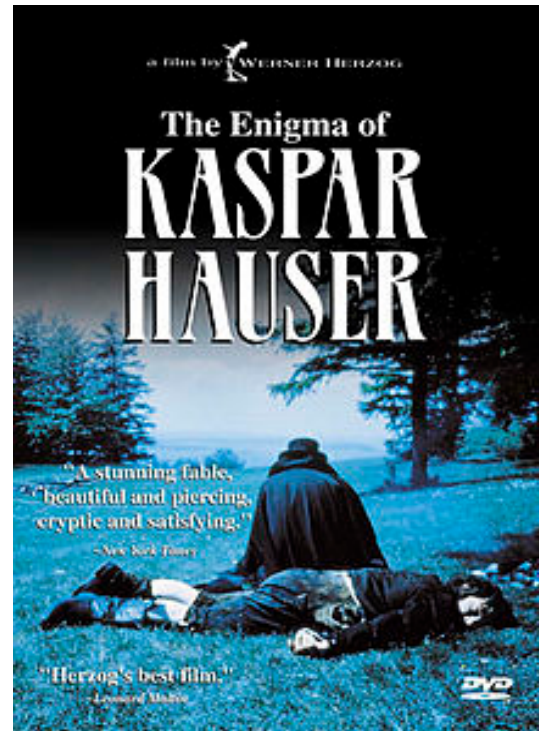


The Tragedy of Alzheimer's

- To become a nonperson

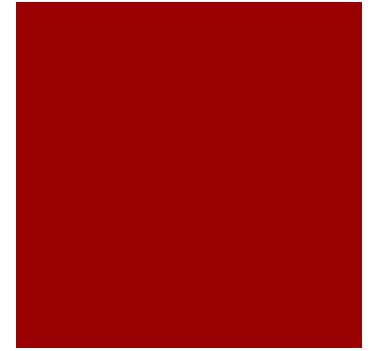


A True Tragedy



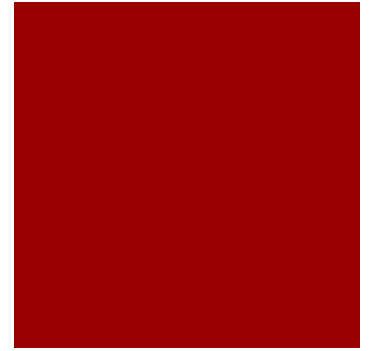
No Tragedy?

- For people in advanced dementia, not being held in personhood is no tragedy
 - The goods of personhood are closed to them no matter what
 - They won't know the difference



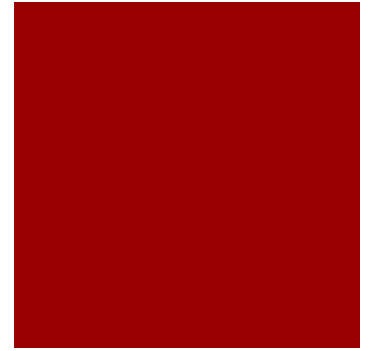
Reply to Objection 2: They won't know the difference

- You can be wronged even if you never find out
 - Rich aunt
 - Jealous friend



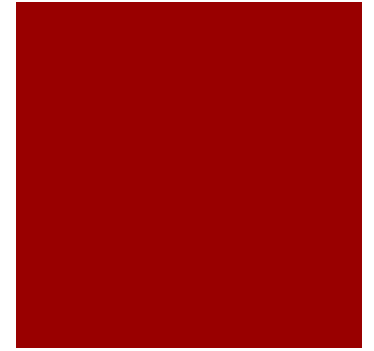
Reply to Objection 1: The goods of personhood are closed

- It matters to us now how we'll be treated later
- We all deserve respect



Health Care Professionals

- Pay attention!



Thank you

This talk is a contribution to the work of the
Consortium on the Ethics of Families in Health and
Social Care.

