



**Speaker:**  
**Laura Green**

**Annual LOROS Lecture**

# **“They talk to me like I don’t know my own body”**

Understanding the experience of  
suffering of older people in hospital

**28th February 2023**

Lecture 5.30-6.30pm

# They talk to me like I don't know my own body

Understanding the experiences of suffering of older people  
in hospital

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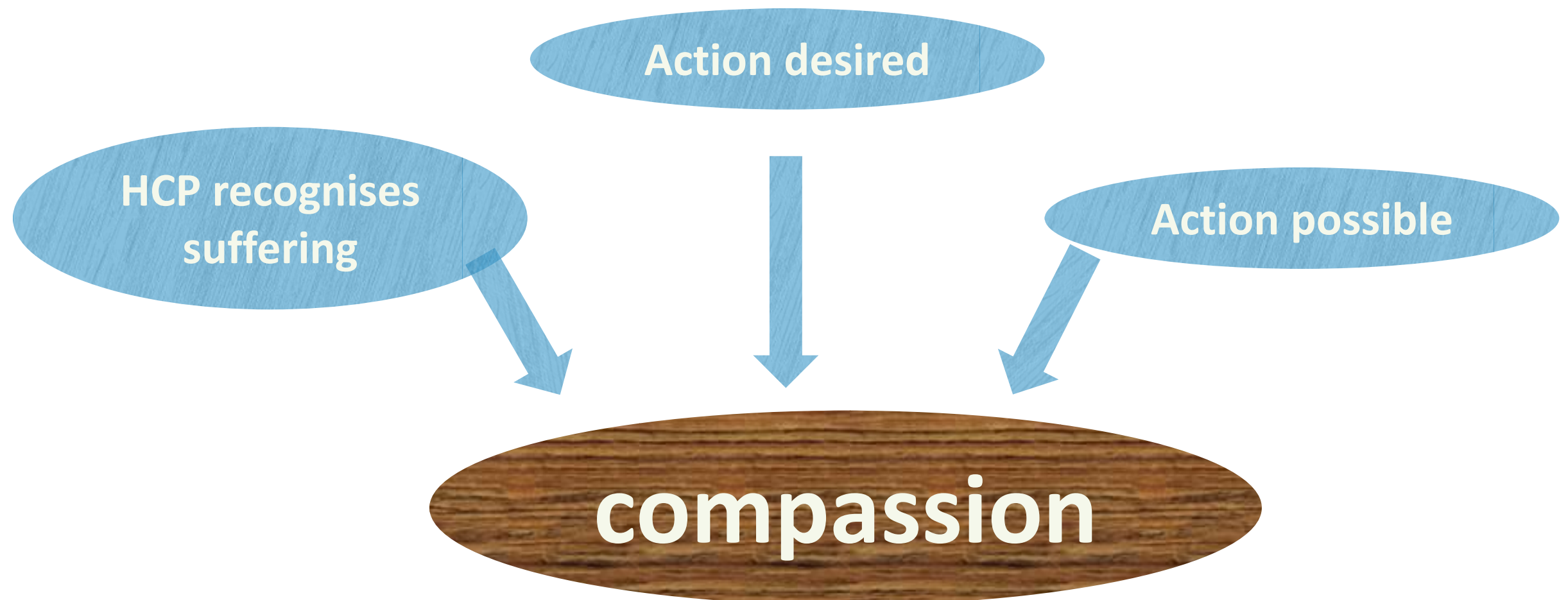
# Background

Francis Report (2013): reports of “compassion deficit”

*“Teach compassion”*

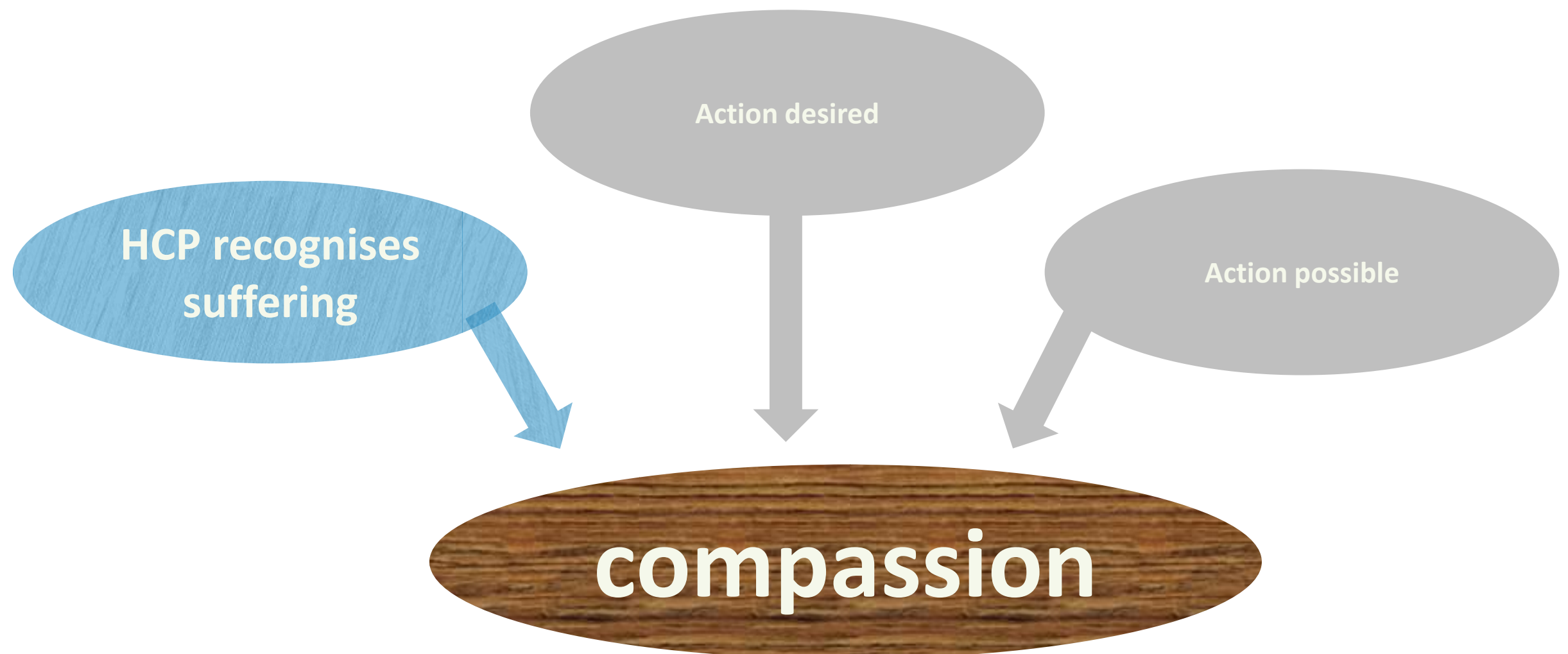
*“Recruit compassionate students”*

# Compassion deconstructed





# Compassion deconstructed



# Suffering and palliative care

Palliative care "prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" (WHO 2002)

# Background

Doctoral study exploring suffering in older people at the end of life

**Setting:** Acute hospital, older peoples' hospital ward in Northern UK

**Ethnography:** 186 hours observation

**Informants:** Patient (n=16), Staff (42), family & visitors (7) Patients: multiple morbidities, ambiguous prognosis, variable capacity, limited involvement in decision-making

# Methods

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- Sensory ethnography
  - Observations – eyes, ears, nose
  - Informal interviews
  - Documentary analysis
- Ethics





# Analysis

- 300,000 words!
- NVivo
- Experts by Experience

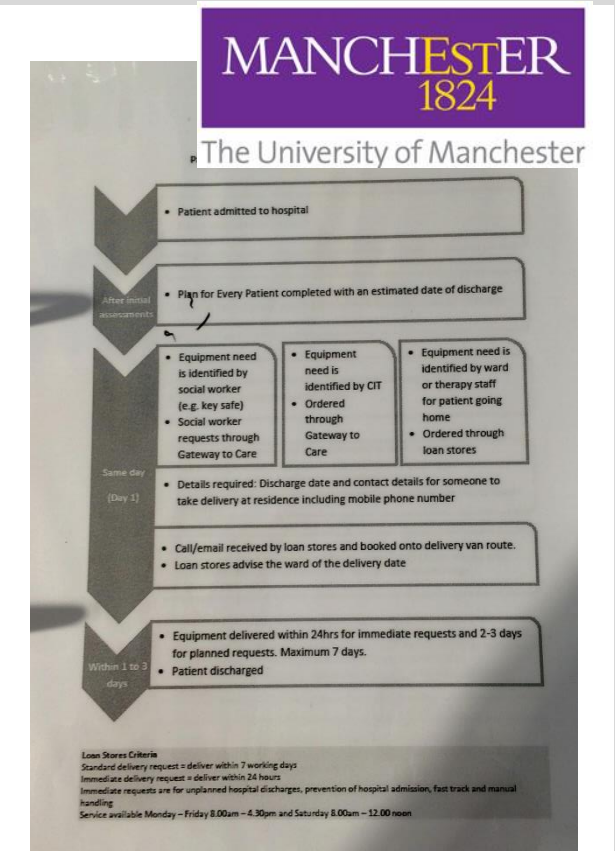
Do you mind my...  
No not at all love  
Well feel free to tell me to go out  
if you'd like some privacy.  
Outside someone is calling out,  
crying 'no' - I only just noticed  
but realise it has been happening  
since I arrived. Then from further  
away 'I want to go home' and  
weeping. Phone rings, Julia answers  
'he chops + changes his mind,  
we are planning on sending him  
over' (H7). Dirty utility receiver.  
Rabbiting trolley wheels. Smell in  
here is of old tobacco smoke,  
illness. V lies back on his bed.  
The ceiling is all he has looked at  
for over a month. Slippers, worn  
and frayed and smelling of urine.  
His ID band is on the floor, he  
must have torn it off overnight.  
VA: (outside, brightly) morning!  
here's your breakfast. Are you  
having it in bed? Buzzer out  
Ha. shouting next door.  
'No! I don't want this'  
'Good morning pet, I'm here  
to let you know breakfast is on  
its way'  
'No!' screaming now.  
V lies with his eyes open. He  
winces, he can hear her.  
Dores off. There is a smear of  
faeces on the floor.

- takes med.  
- sleeps well  
- polite

Comment  
process.

Tuning out

Ta. weeping  
been crying since she arrived?  
V sleeping. I leave. Return to safety of  
the pod. Jane has fallen, her crying is  
louder.  
- Elaine - you're alright.  
J. I'm not alright! Weeping  
Julia is called out of room to come +  
help. The sound of her crying is awful.  
'I want to go home'  
Will she stand for us?  
No I don't think so. Jane will you stand?  
I can't. I can't. (can't consent, too  
distressed) Consent.  
Did you hurt yourself?  
- me back, it's hurting more + more.  
(she's back in bed now)  
- Do you want a drink?  
- No I don't.  
loud beeping, Elaine brings a falls  
alarm. It crackles + she waits  
- Elaine - that's it, you're done. Do you  
want some muller?  
(whispering, weeping). (It sounds like  
an exhausted toddler cry)  
Rita's bed is empty - pang of sadness  
that I won't see her again.  
Neal - Julia talking about off duty, constant  
issue. Elaine is wither Elaine discussing  
pressures of changing from nights to days  
all in a week.  
I see how Cl. is. Not too bad this am  
(Vest + Julia). We shaved him - he didn't  
really want me but he looked a bit  
washed.



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# Key finding 1: Iatrogenesis

◆ **Iatrogenic suffering** can result from well-intentioned interventions:

- ◆ Interventions (investigations, defensive medicine)
- ◆ Environment (noise, routines, odours, time)
- ◆ Interactions (malignant social psychology)

# Interactions

- *Tom and Vincent*
- *Rita and 'the ward round'*



# Environment

*“I wanted, I thought, only a little,  
two teaspoons of silence”  
(Hirshfield, 2015, p63)*

- Janice and the commode
- Vincent and drilling
- Alfie and the doors



*We leave Alfie's room. "He thinks he's going home", I say to Kirsty.*

*"They all think they're going home", she replies.*



# Interventions: Ned

94 years old

Dementia for past 4 years

Widowed

Admitted with chest infection - ?aspiration pneumonia

Weight loss, response to antibiotics uncertain

Deemed no capacity



# Interventions: Ned

Consultant: “I think of it as a battlefield, when we have someone in front of me who is moribund we do everything. But my other hat is as a human being...he's 94, lives alone, wife died...is it treating with all the tubes and things that are giving more trouble? The only reason I support the feeding is that he wasn't bedbound, he was mobile. If he had been bedbound, incontinent, needing all cares, I would have been different.”

Daughter: “It's difficult, isn't it? How long would it be for? Forever? He loves shepherd's pie”

“I will be guided by you. We can take a risk and feed him by mouth”



Ned's daughter goes back into his room and takes the NBM sign from the door. "guess what dad, they've said you're allowed some lunch" "oh good" - a mug of soup is brought and she begins to feed him.

He slurps a spoonful, coughs, smiles and sighs.

"I were bloody starving."

# Interventions: Ellen

Ellen (64) : Background: Stage IV heart failure, deteriorating renal function

Unconscious on arrival following seizure/stroke. Does not wake up fully

Family with her most of time; telling her to get better

Family concerned because: she has not eaten for 3 days and staff don't seem to be concerned

Nurses (outside room) discuss probably dying: this has not been discussed with family – “the consultant needs to make the decision”

Over weekend, family distressed - on-call dietician places nasogastric tube, feed is commenced

“You've just given up on her”

# Ellen

Increasing oedema

Vomiting and aspiration

Metoclopramide syringe driver commenced

Sited in arm – oedema – ineffective – resited centrally

Pressure sore to nostril

Nurses distressed ++

# Ellen

Discussions about dying curtailed twice due to family distress and anger, & professional anxiety about talking about dying

Medics retract due to clinical ambiguity

5 days later doctor tells family Ellen is dying. Feed discontinued, tube removed, other family called to bedside. Dies three hours later.

Nurses angry ++





I enter Ellen's room. Her family have gone home and mercifully her nasogastric tube has now been removed. Her light has been turned down low; I can hear her breath, rasping. Alvar is leant over her; with a piece of soft gauze and a plastic tub of warm water he is gently and methodically wiping the crusted blood and mucous from her nostrils, lips and tongue. She is not responding - her tongue is swollen and her eyes bulge. The swelling in her arms has worsened and her skin is shiny, mottled, cold. I stand in silence and watch. He does not respond to me other than to acknowledge my presence. Then, some moments later, says "there are two kinds of nurses, there are those who spend an extra five minutes after the main jobs are done and those who don't. When my grandfather was dying, I noticed this". He dabs vaseline on to her lips. "When people are old, it's like organic, the body starts to fail. It is natural. I could never do paediatrics because that is not natural. She is not suffering now".

It's the fourth day of my observations, and the first time I have heard the word "suffering" mentioned. I look at Ellen.

"No", I agree, "she is not suffering".

## Key finding 2: ideologies of care

Clinical practice informed by **ideologies** and bound by (unspoken) **rules**

The rules:

- are often shared by members of professions
- dictate decisions at key times
- help individuals navigate uncertainty



Acute care



Care of the Elderly



Palliative care



A person in a hospital hallway, possibly a nurse or doctor, walking away from the camera. The scene is overlaid with a red emergency light effect, suggesting a rescue or urgent situation.

# RESCUE

“Scoring 4 on the MEWS”

Two elderly people, one wearing a cap, walking away from the camera in a hospital hallway. A sign on the wall reads 'COURT SEJOUR GERIATRIQUE'. The scene is overlaid with a semi-transparent black box containing the word 'REHABILITATION'.

# REHABILITATION

“I’ll just go through my green crosses”

An elderly person lying in a hospital bed, covered with a white blanket. The scene is overlaid with a semi-transparent black box containing the word 'RELEASE'.

# RELEASE

“The gift of a good death”



# Not all ideologies are equal

Care is generally good when team agree on approach

Problems arise when:

- Care transitions from one approach to another
- Patient, families or professionals disagree about correct approach

Society values heroism, battling against death, power of medical technology and bioscience

The "rescue ideology" dominates

# Rescue

Ellen: Dying on admission. Palliative approach indicated

uncertainty of diagnosis



uncertainty of prognosis

Uncertainty



rigid adherence to rules

# Rescue

- Uncertainty is difficult; leads to increased adherence to “the rules”
- The "**ideology of rescue**" dominates: default position in acute hospital ward
- **Iatrogenic suffering** can result from well-intentioned interventions



Multidisciplinary meetings; goal of care

Schwartz rounds / mortality review

Asking "the question"

Informant involvement: making the invisible visible

Recommendations – for practice



Interprofessional learning

Observational methods in health professional education

Reflection without proficiencies

Recommendations – for education



Do observational methods offer insight into situated nature of ethically challenging situations?

What is the impact of professional differences in capital in terms of agency and decision-making?

What policy developments can enable development of shared habitus?

Recommendations – for research



“We are the guardians of what we witnessed” [Behar 2014]

