Joint Select Committee on End of Life Choices

Perth, 9 March 2018

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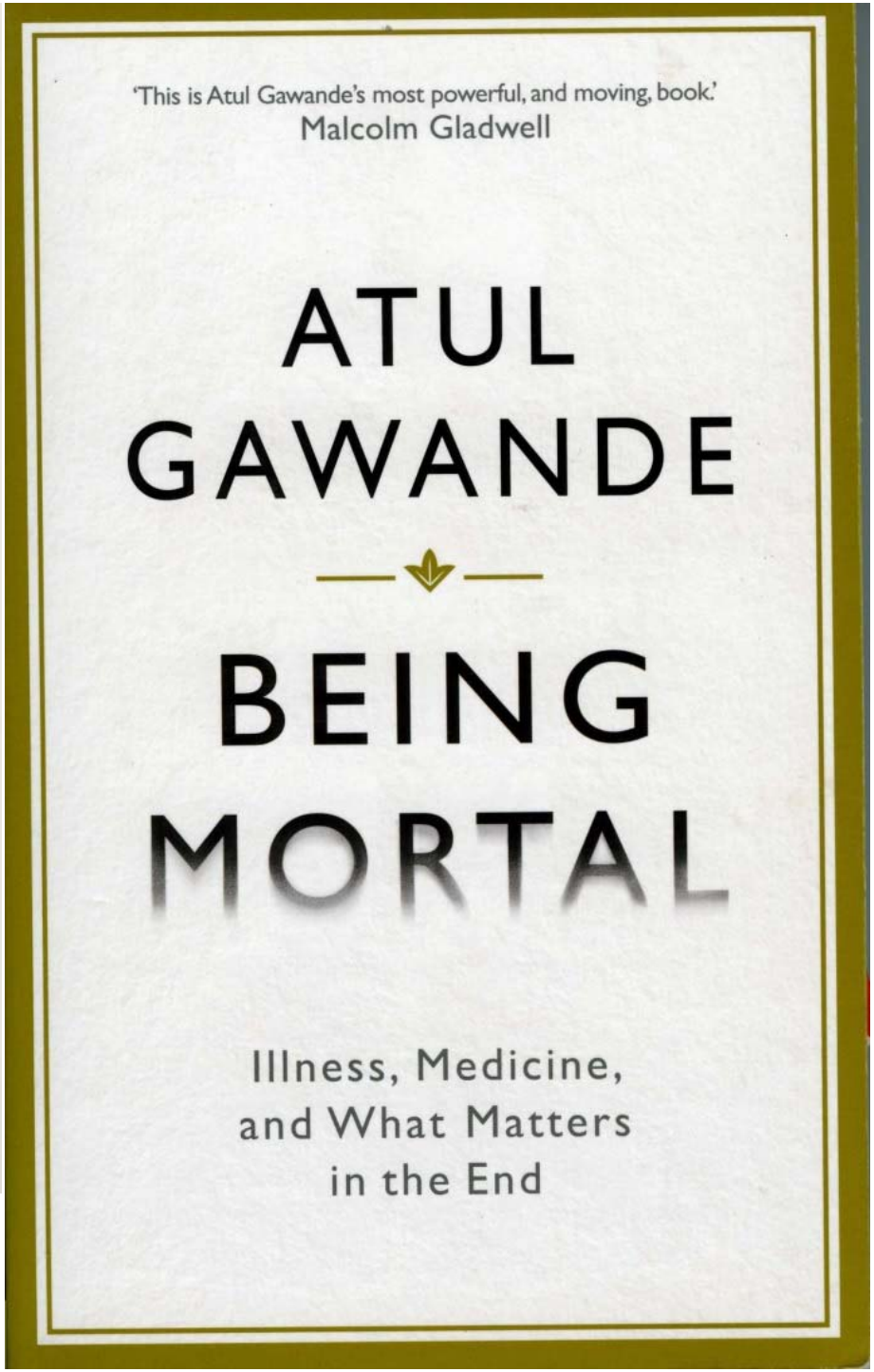
BRIGHAM AND WOMEN'S HOSPITAL
Atul Gawande, M.D., M.P.H.
Department of Surgery


'This is Atul Gawande's most powerful, and moving, book.'
Malcolm Gladwell
ATUL GAWANDE
BEING MORTAL
Illness, Medicine, and What Matters in the End

Being Mortal

“For most of human history, death was a common, ever-present possibility. But now, as medical advances push the boundaries of survival further each year, we have become increasingly detached from the reality of being mortal.”

From the rear cover

Being mortal

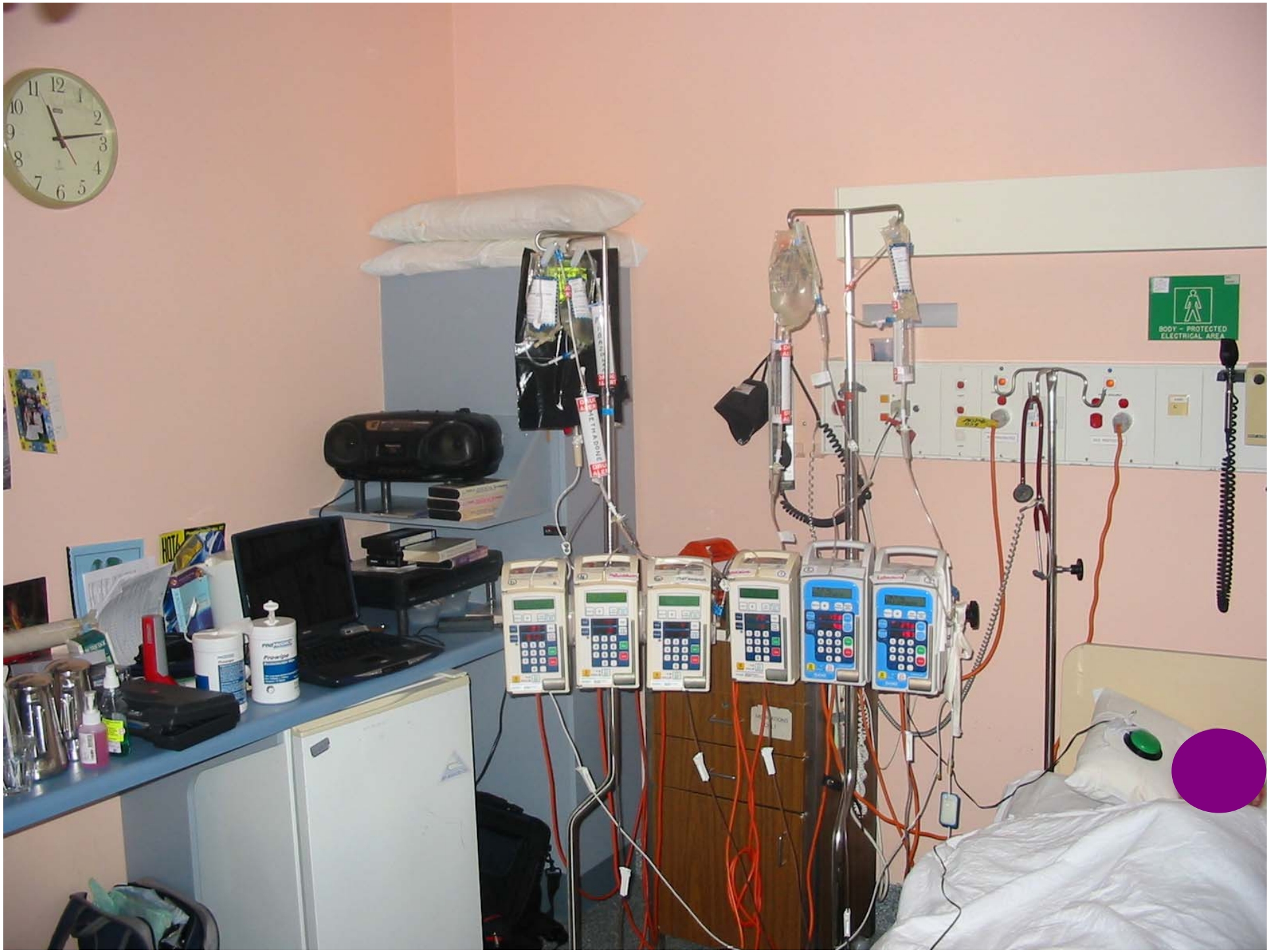
"Medicine's focus is narrow. Medical professionals concentrate on ***repair of health, not sustenance of the soul.*** For more than half a century now, we have treated the trials of sickness, ageing, and mortality as medical concerns. It's been an experiment in social engineering, putting our fates in the hands of people valued more for their ***technical prowess*** than for their ***understanding of human needs***.

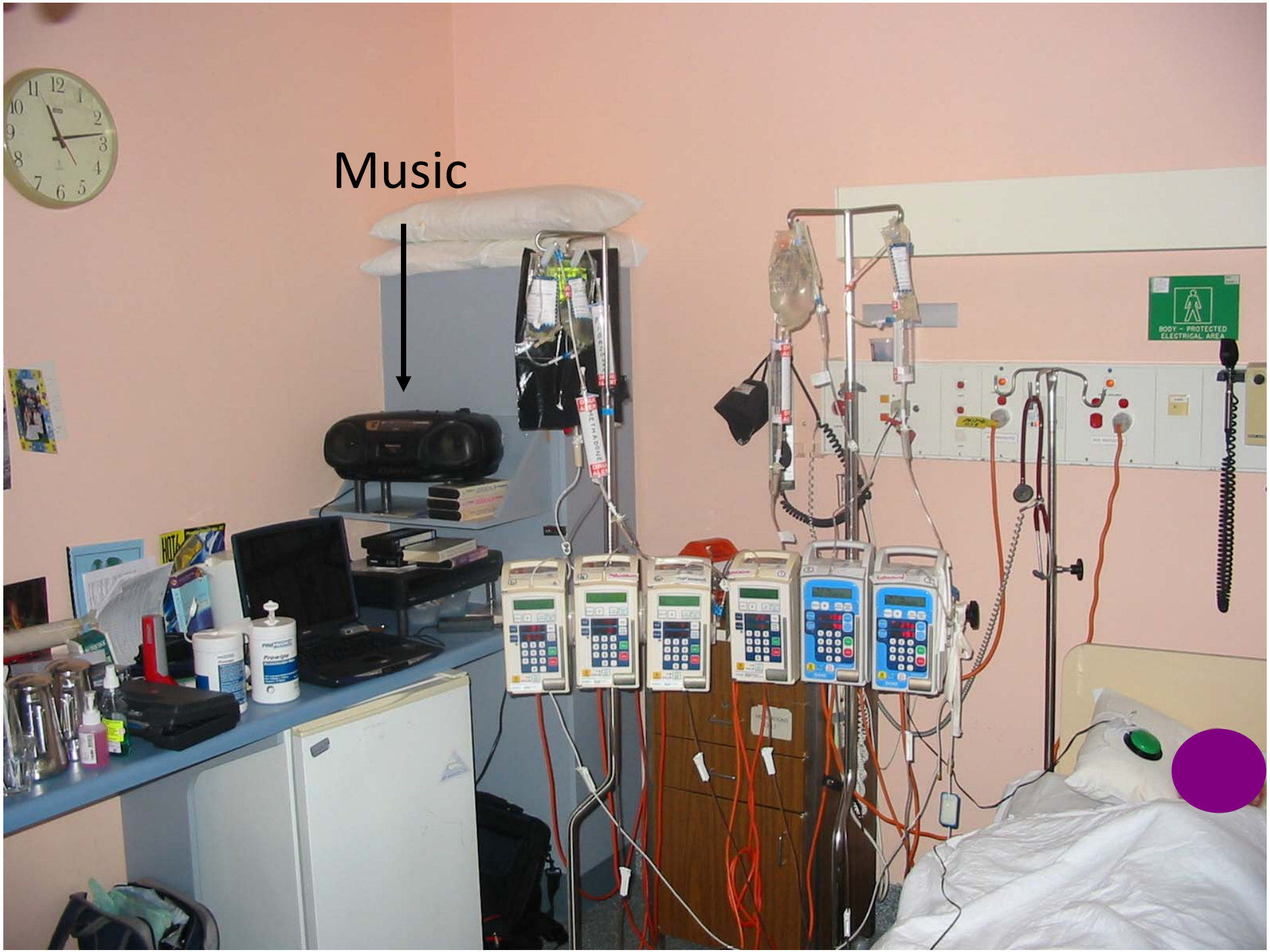
That experiment has failed."

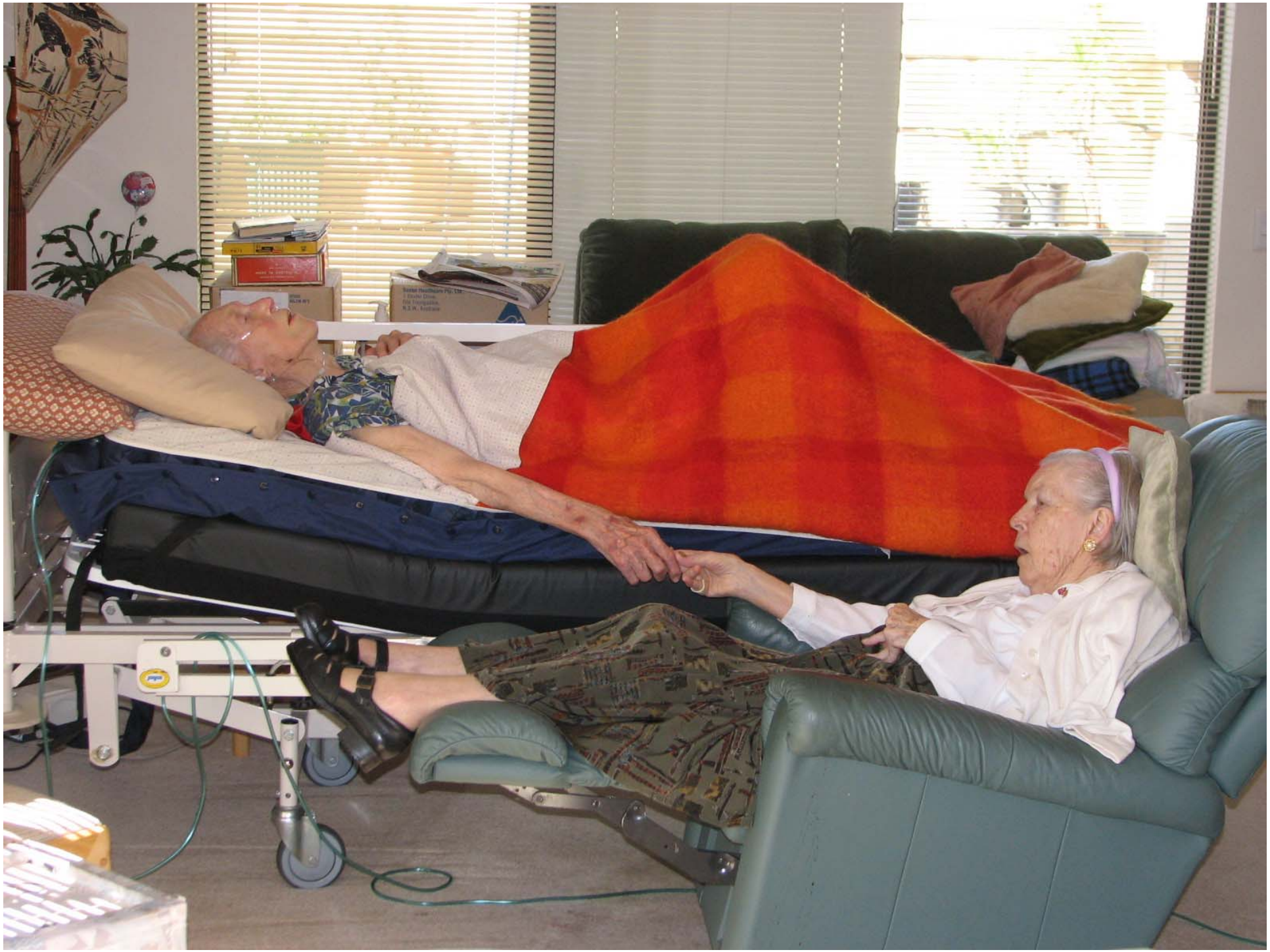
p128

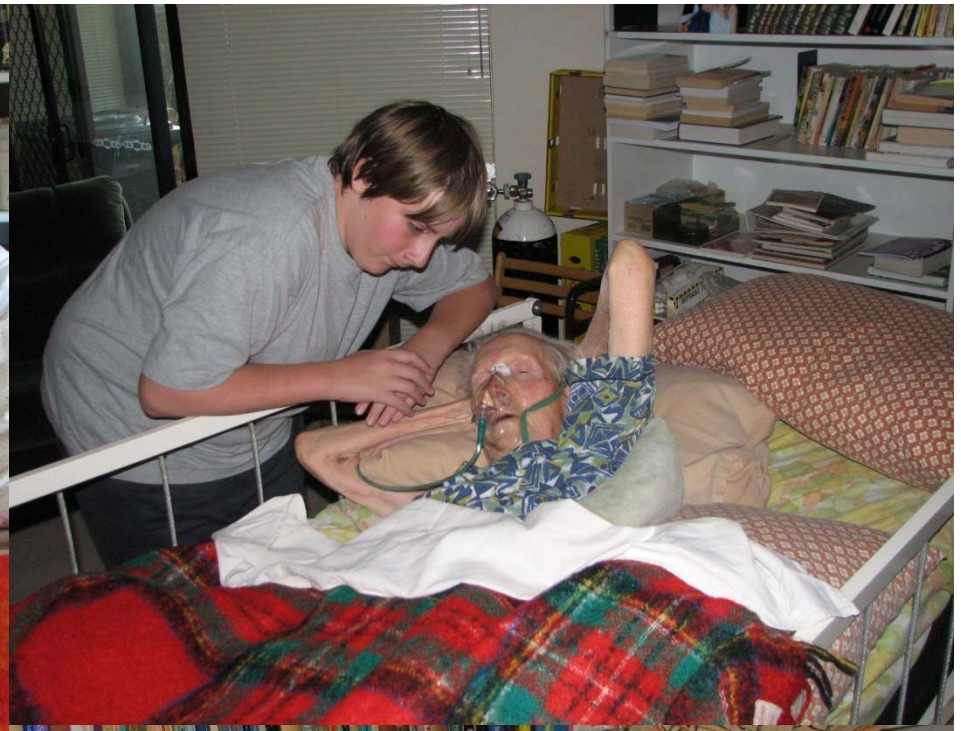
End-of-life suffering and patient choice

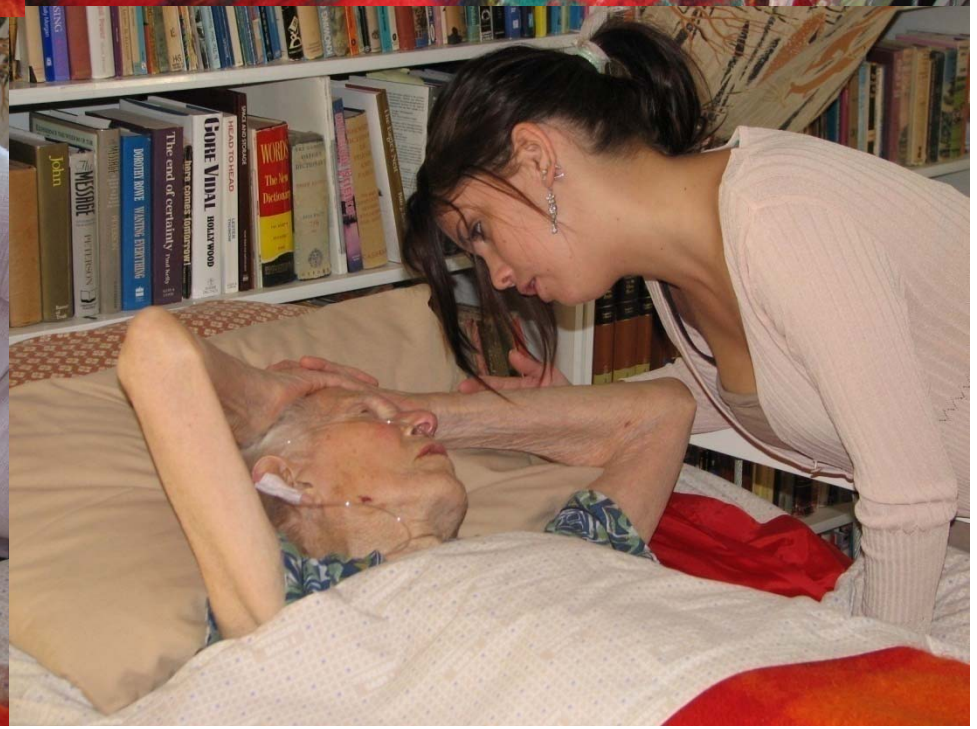
- Medical school education emphasises curing diseases, using technology and pharmacology
- When both the doctor and the patient avoid facing the reality of death, the result can be a prolonged, distressing, agitated, fearful, lonely death, on a hospital bed, entangled in tubes, instead of in the embrace of a loving family.
- In other words, the patient receives expensive, futile treatment which ***increases*** suffering.


BODY - PROTECTED
ELECTRICAL AREA


Music
BODY - PROTECTED ELECTRICAL AREA






WORD
The Net Dictionary

Royal Perth Hospital PALLIATIVE CARE SERVICE

……is dying. The goal of care is **comfort, dignity** and **family support**, not prolongation of dying.

Considerations:

1. Ensure the family are aware and in agreement
2. Agree on the place of death: hospital, hospice or home
3. Cease unnecessary observations, medications and investigations
4. Remove unnecessary tubes and devices
5. Cease artificial nutrition and hydration

6. Prevent pain, dyspnoea, nausea, secretions and agitation

7. Give good mouth care, regular turning, comfortable mattress

8. Provide a chair/bed/mattress for relatives

9. Offer support from pastoral care (chaplaincy)

10. MET calls and CPR are not appropriate

For further advice page the palliative care registrar 2529, or nurse 2371

Royal Australasian College Physicians
Chapter of Palliative Medicine
Advanced Training Curriculum

DOMAIN 1 MEDICAL EXPERT/CLINICAL DECISION MAKER
Theme 1.8 Understand the Role of Spirituality in the Experience of Patients, Their Families, and Carers

Learning Objective 1.8.1

Recognise that spirituality, however expressed, is a key dimension of the human experience and understand how spiritual issues can impact on suffering

Palliative care in the wheatbelt

A report by Nurse Manager Brett Hayes

An inpatient, outpatient and consultancy service

- 157,000Km^2 (England is 130,000 km$^{2)}$
- 24 hospitals
- 8 nursing posts
- 38 residential aged care facilities and their communities.

Staff: 1 Full time Nurse Manager, 1 Part time Clinical Nurse,

1 Part time Social Worker, 1 part time Admin assistant

Once a month a very dedicated Palliative Care Medical Specialist.

“Bad deaths in country WA”

A terminal patient presented to Southern Cross Hospital after hours. . . The patient was seen by the Emergency Telehealth Service (ETS) in the ED. The decision was made to admit the patient, but with no doctor with admitting rights available, the patient was transferred to Merredin hospital, 109km away from home. Merredin hospital had no admitting doctors so the patient was sent to Northam Hospital, 271 Km from home. Northam Hospital had no beds so the patient was transferred to Perth. The patient died alone in an ED in Perth, 360km from home.

A terminal patient from Beverly presented to Beverly Hospital ED after hours. There was no doctor available with admitting right so the ETS in the ED arranged for the patient to be transferred to Armadale. The patient died in the ambulance.

Misunderstanding about morphine “killing people”

“My father was secretly euthanased. The nurse gave him an injection of morphine and he died three hours later.”

A true report

A 54 year old man with metastatic renal cell (kidney) cancer. Pain had been controlled with an intrathecal infusion of opioid and anaesthetic, ie injected directly into the spinal fluid.

Given 30mg ampoules of morphine x 20 = 600mg intravenously in one hour, but was still wide awake, pleading for more analgesia!

Food and fluids: confusing terminology

Fasting

Voluntary refusal of food and fluids

Hunger strike

Starving to death

Dying of thirst

Palliative starvation

See the RPH brochure *Is he hungry or thirsty?*

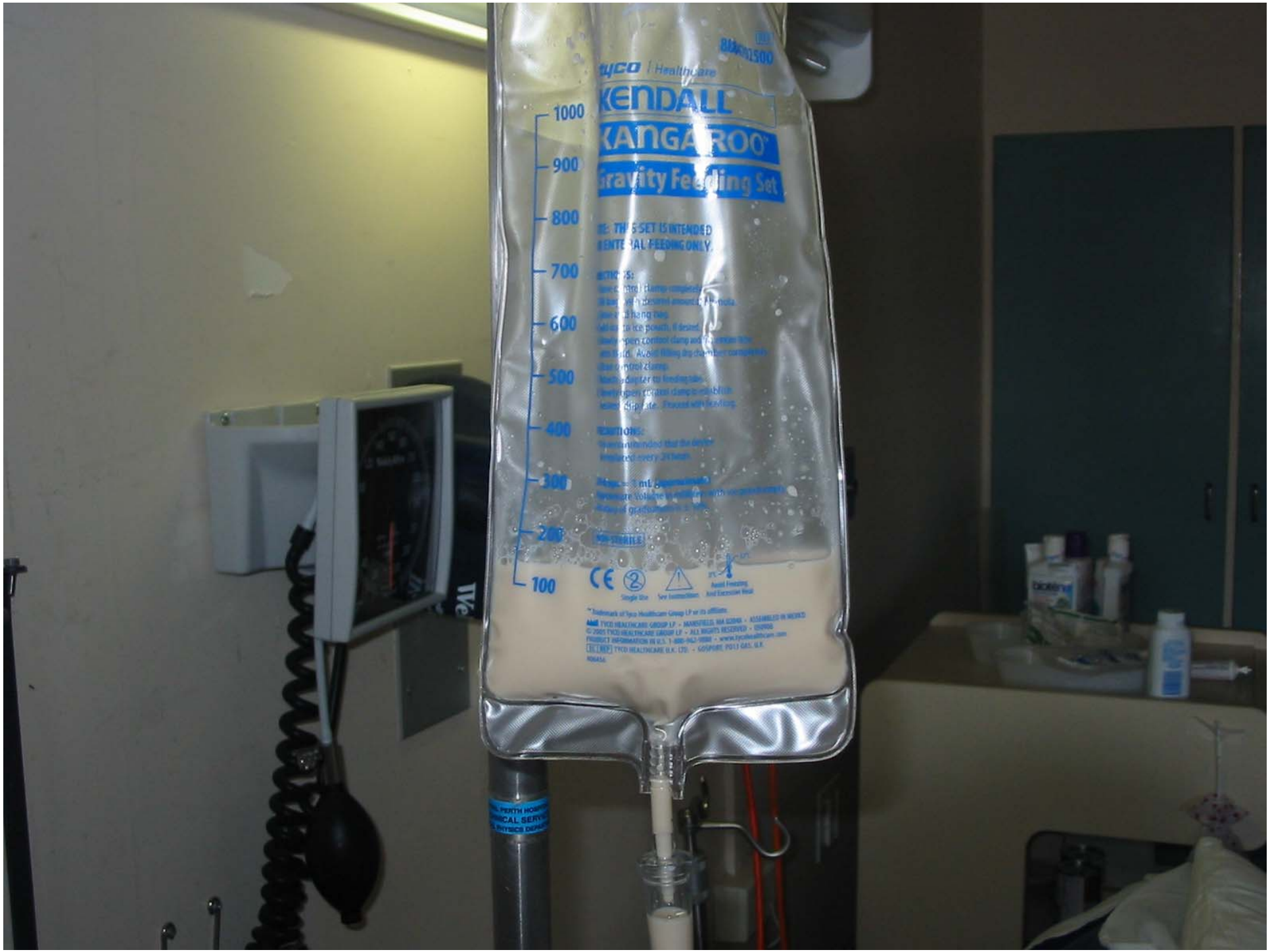
Misunderstanding about fasting

Andrew Denton

"Of all the things I learnt over the last eight months, **the most shocking** was this: there is one circumstance in which Palliative Care Australia will accept a patient's right to hasten their own death – which is to refuse treatment, including food and water, until they die.

Seared into my brain is the conversation I had with Professor Richard Chye, the head of palliative care at St Vincent's – a gifted physician and teacher who, when I asked how long it can take for a patient to die this way, told me it could take *weeks* – weeks which were **psychologically painful for both the person dying and their family watching on**".

https://www.wheelercentre.com/notes/denton-s-di-gribble-argument-2015


tyco Healthcare
KENDALL
KANGAROO
Gravity Feeding Set
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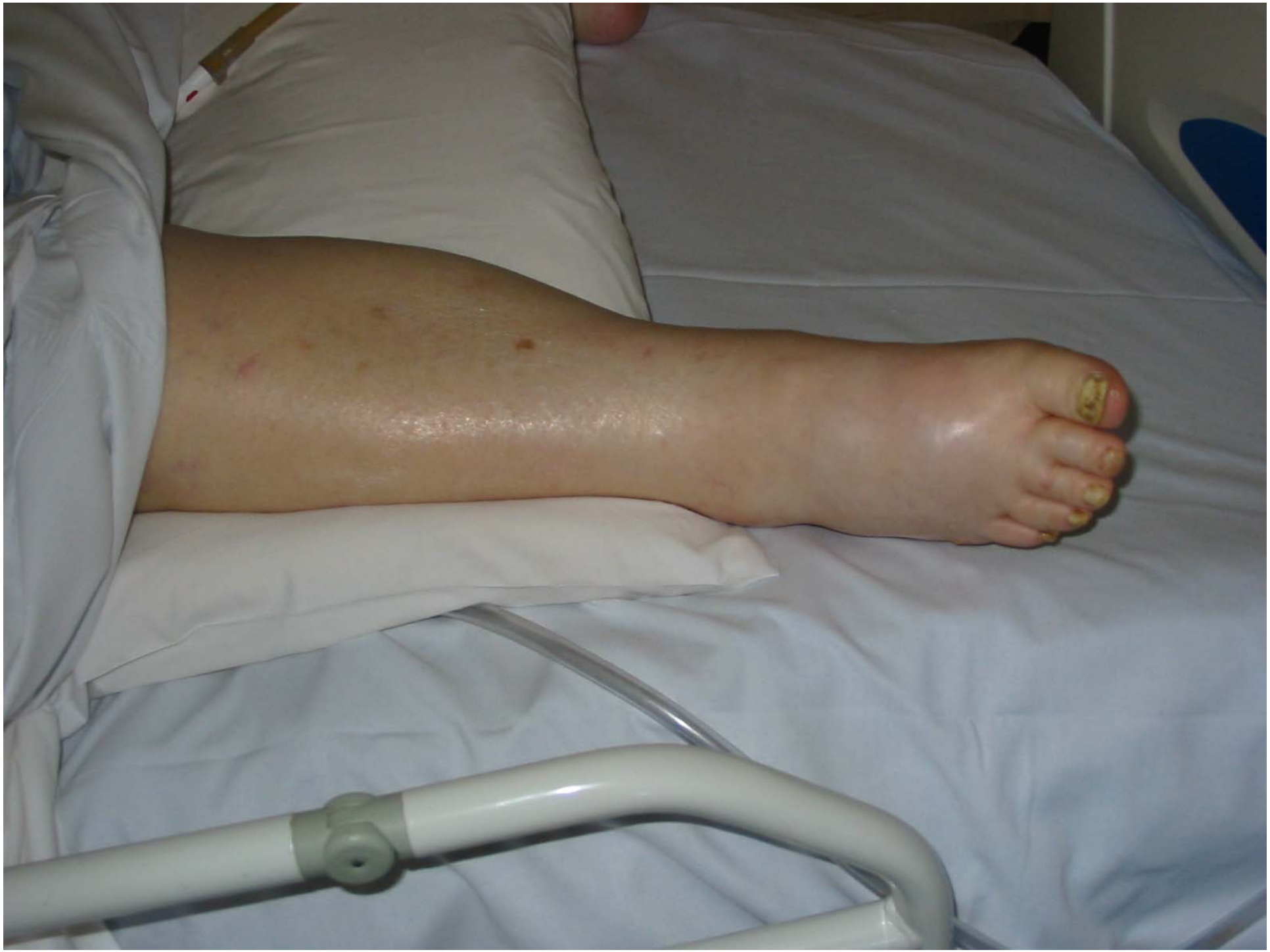
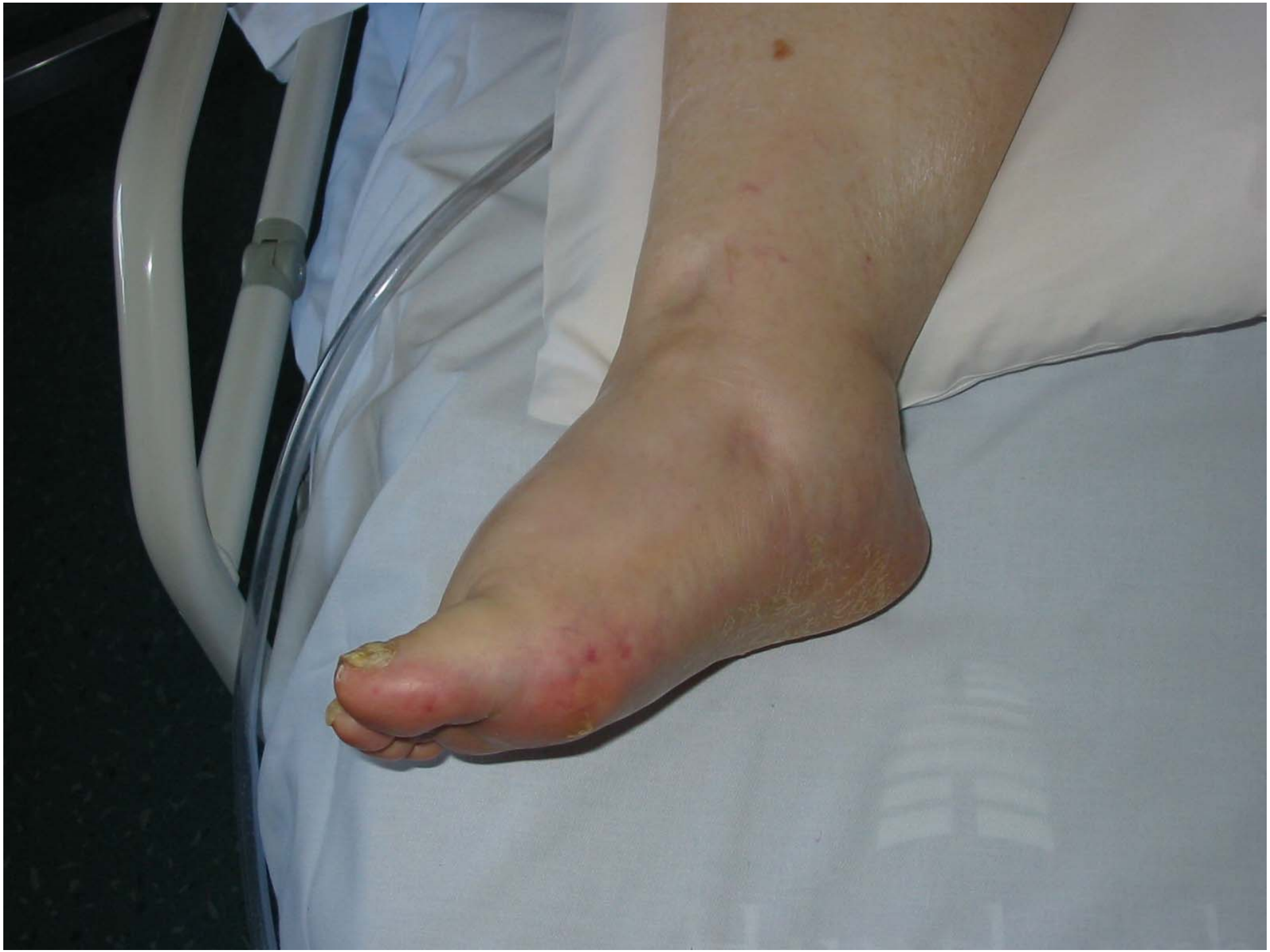
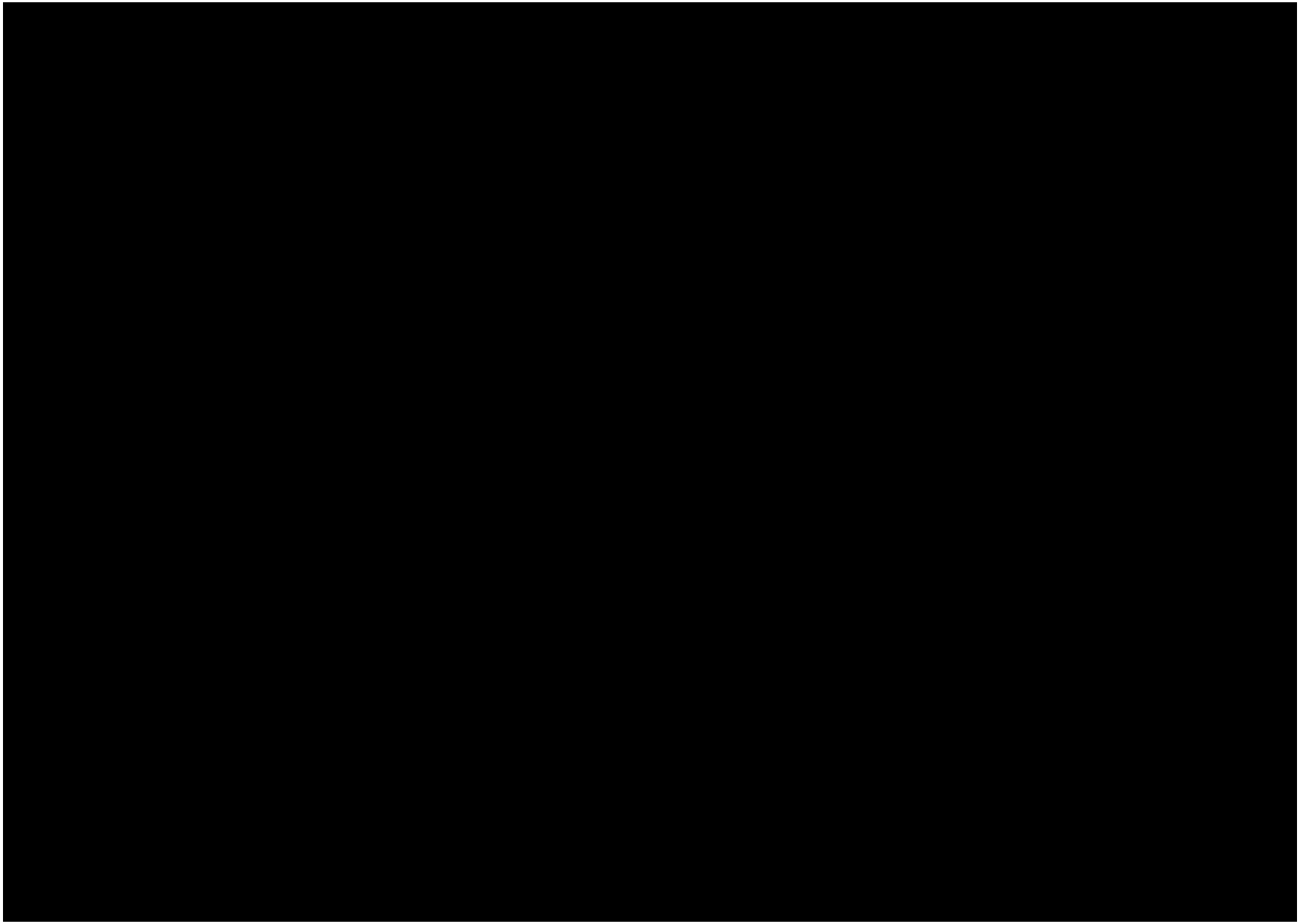




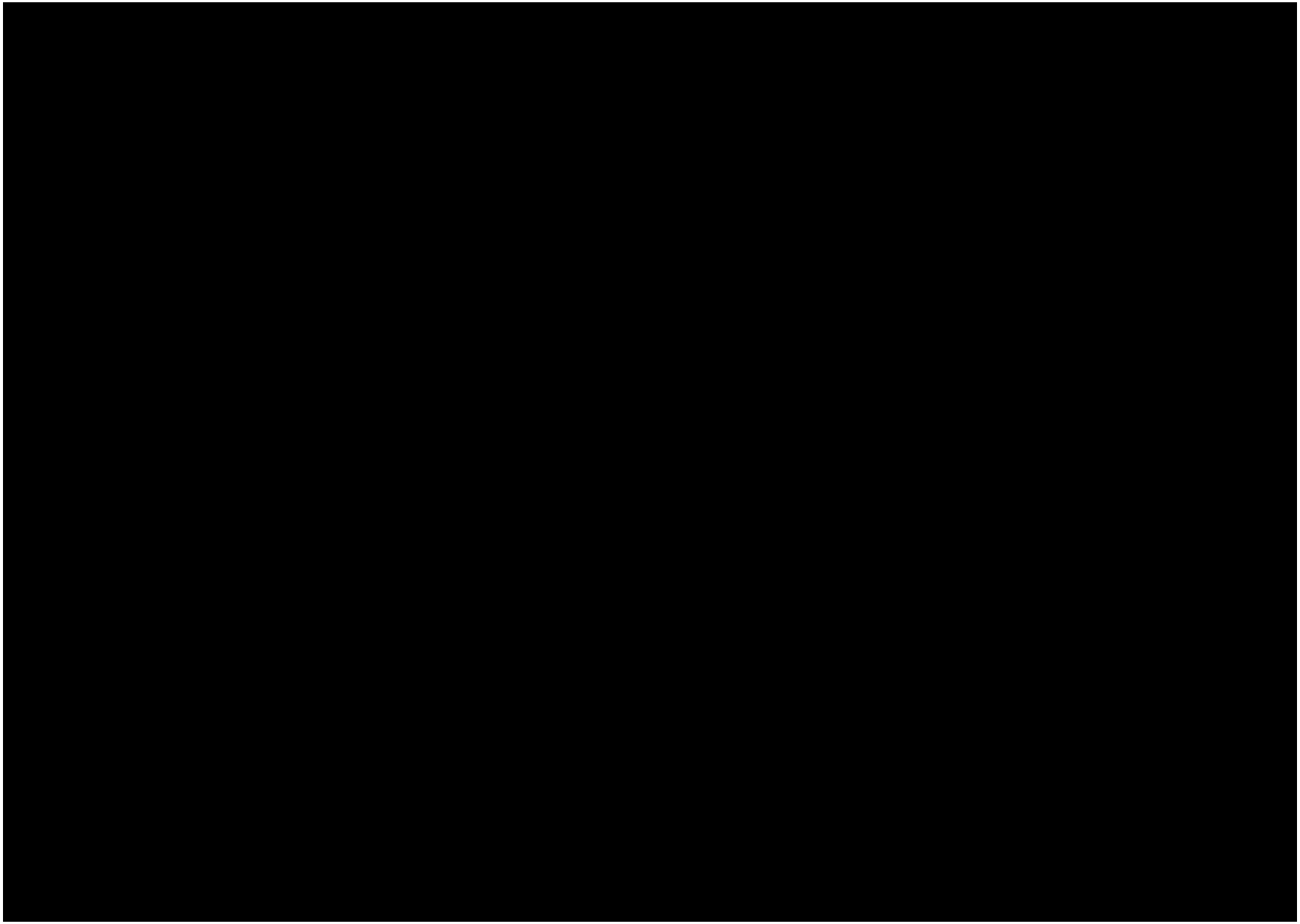


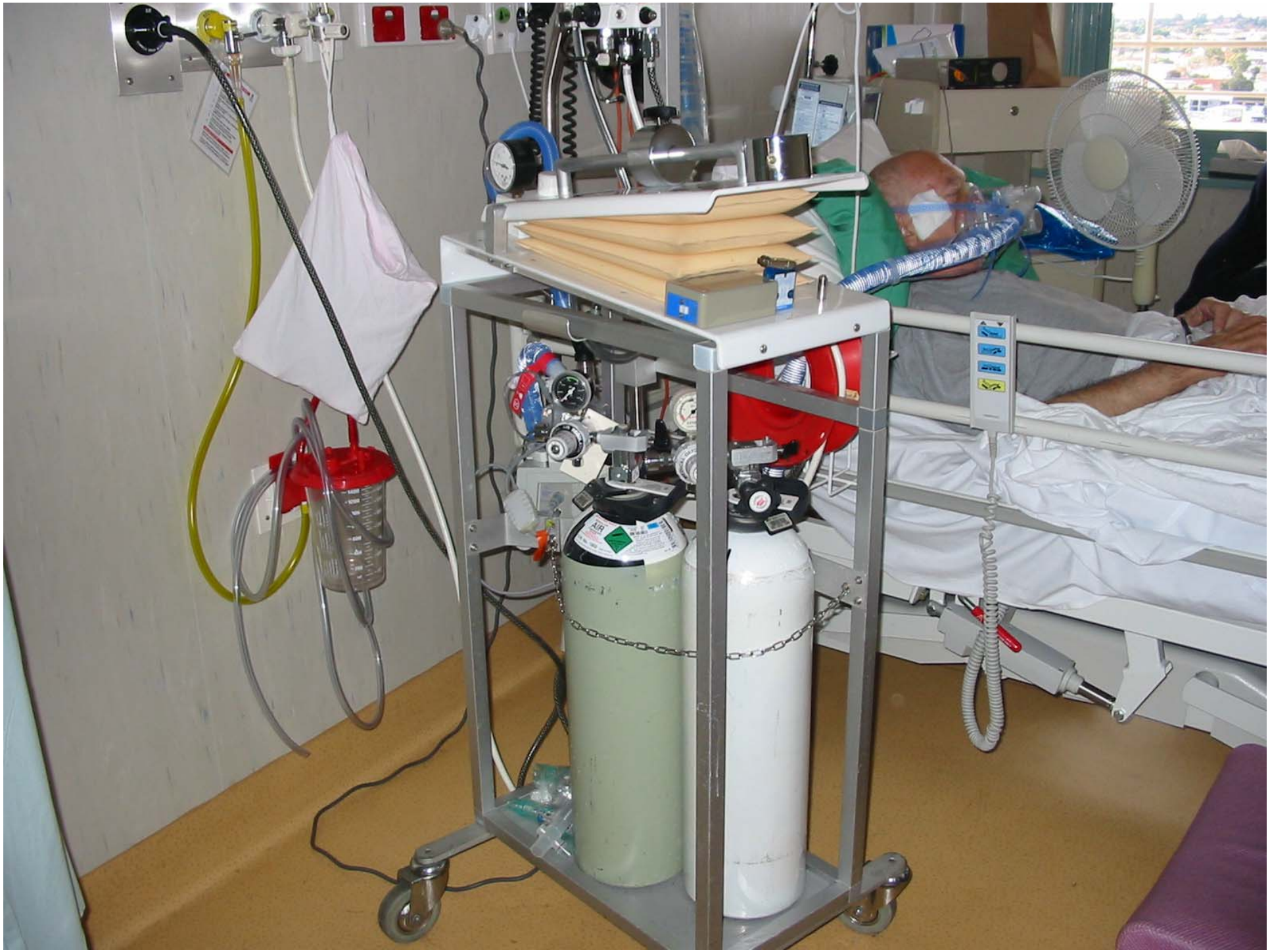
Misunderstanding about withdrawing ventilation

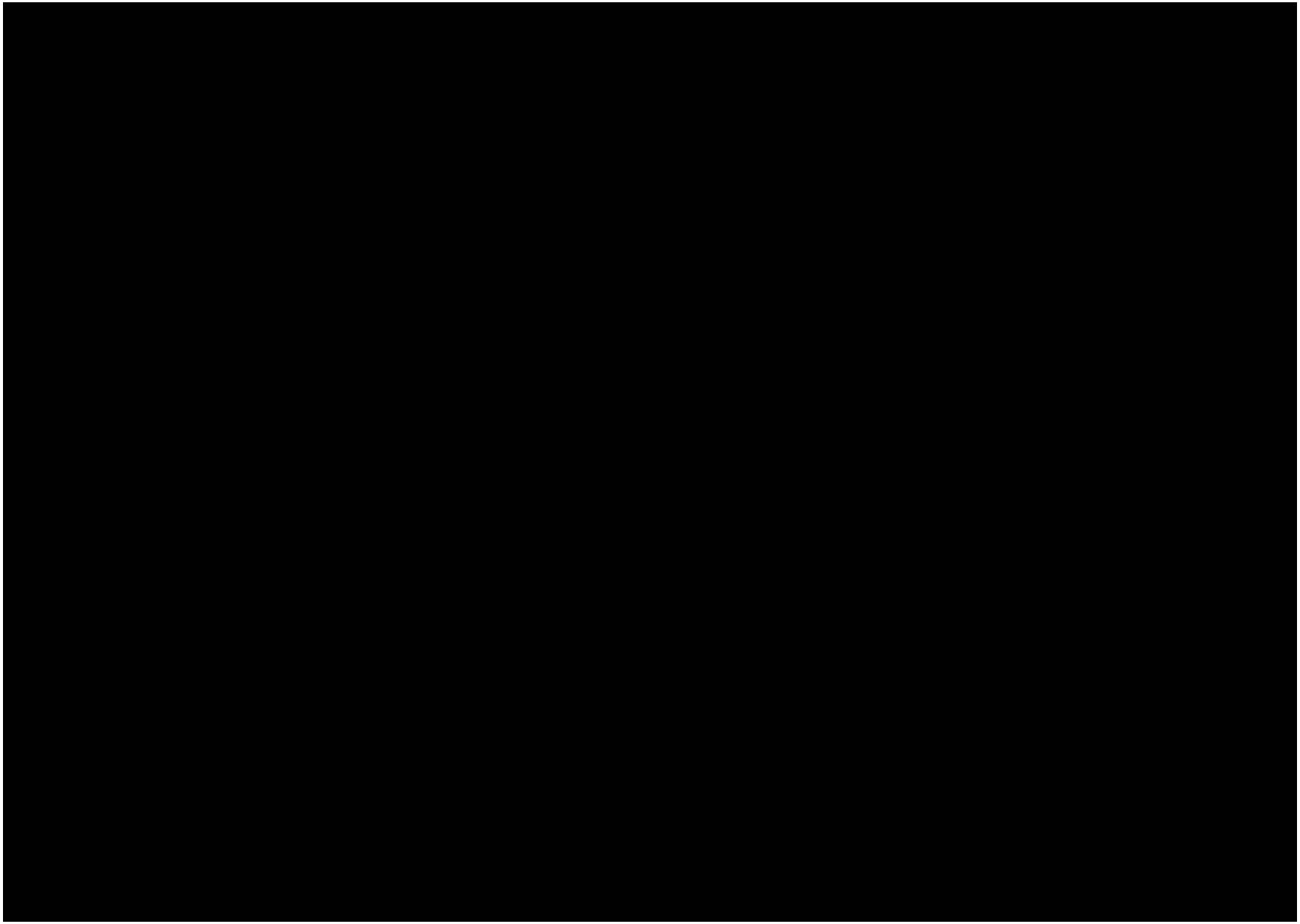
The problem

- A conscious patient who says:

  “sedate me, take off my mask, and let me die”
- The fine line between ethical withdrawal of futile therapy, and euthanasia
- The doctor’s irrational feeling, “I am killing my patient”
- Giving enough sedation to prevent a horrible, choking death, but not so much as to kill
- What are the best drugs, doses, rates and routes?

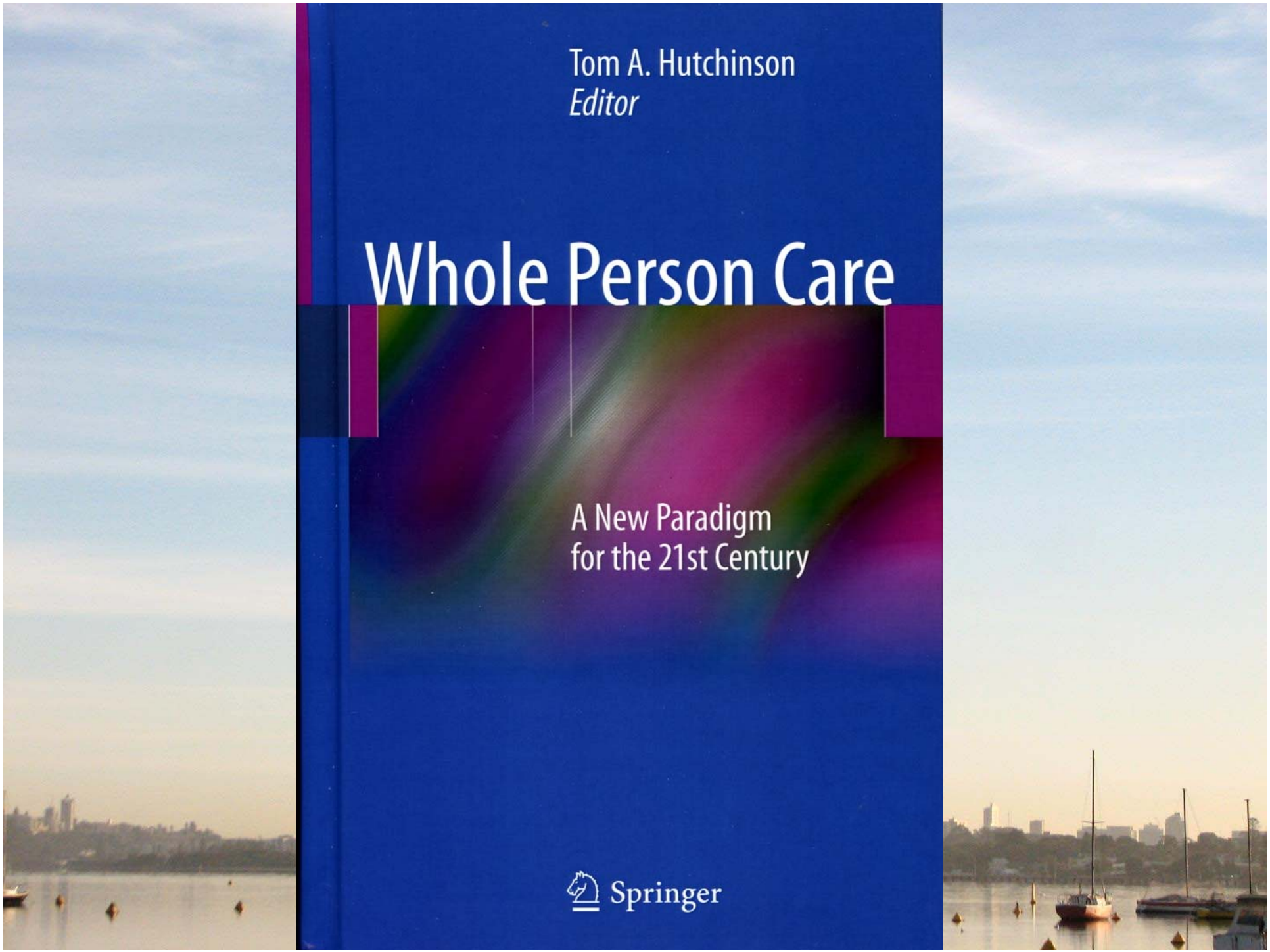






Prof Balfour Mount,
who coined the term “palliative care”
Comment on euthanasia in Canada

One final comment: I remain disturbed by the acronym ***‘MAiD’*** ("Medical Assistance in Dying") promoted by the Canadian forces favouring euthanasia. Misleading! Dishonest! How strange!!! I was under the impression that “medical aid in dying" was what I had been doing over the past half century. However, it *was* a clever, if devious, choice of an acronym, with its inherent subtle suggestion of the process involving a caring maiden.....


Tom A. Hutchinson
Editor
Whole Person Care
A New Paradigm
for the 21st Century
Springer

Whole Person Care
The medical dichotomy

	Hippocratic	**Asklepian**
Patient		
Problem	Symptoms or dysfunction	Suffering
Possibility	Being cured	Healing
Action	Holding on	Letting go
Goal	Survival	Growth
Self image	At the effect of disease	Responsible for coping with illness
Doctor		
Focus	Disease	Person with illness
Communication	Content Digital Conscious	Relationship Analogue Unconscious
Power	Power differential	Power-sharing
Presence	Competent technician	Wounded healer
Epistemology	Scientific	Artistic
Management	Standardised	Individualised
Effect	Real	"Placebo"

Whole Person Care
The medical dichotomy

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