Ageing and Dying Well - design challenges for the end of life -

Matthias RAUTERBERG 2023



WHAT IS LIFE? The Physical Aspect of the Living Cell

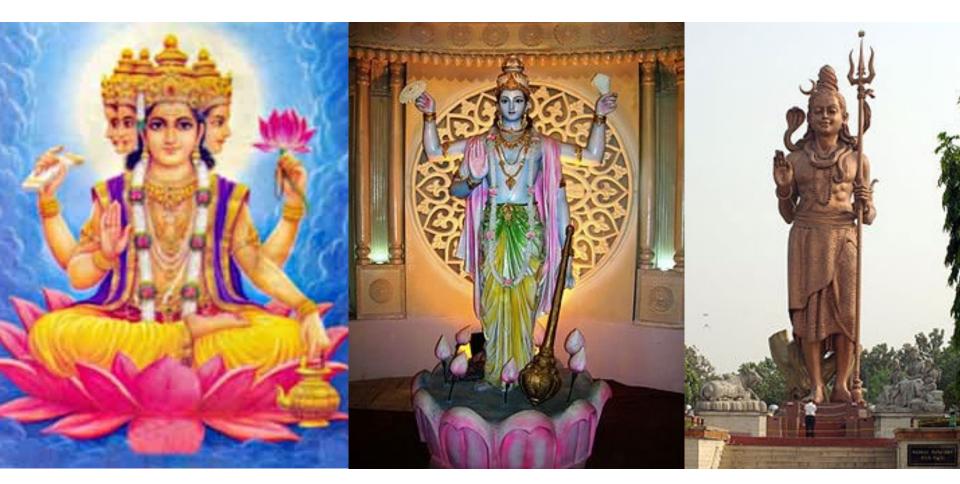
BY

ERWIN SCHRÖDINGER

SENIOR PROFESSOR AT THE DUBLIN INSTITUTE FOR ADVANCED STUDIES



Brahma, Vishnu, and Shiva



The creator

The preserver

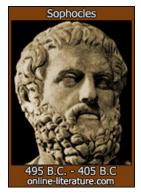
The destroyer

The Oedipus trilogy

love

power

death



SOPHOCLES [429 BC]



[pictures taken from http://en.wikipedia.org/wiki/Oedipus_the_King]

The three psycho-analytical schools

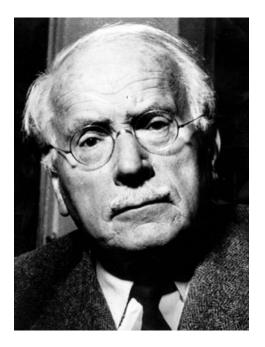
love





Alfred ADLER

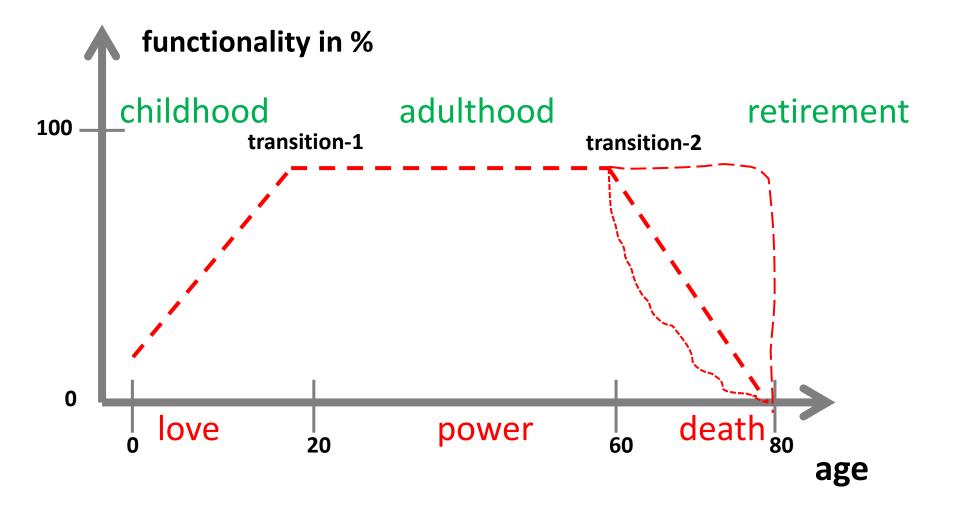
death



Carl G JUNG

Sigmund FREUD

Three phases in life...



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A 12th-century Byzantine manuscript of the Hippocratic Oath

I swear to fulfill, to the best of my ability and judgment, this covenant:

I will respect the hard-won scientific gains of those physicians in whose steps I walk, and gladly share such knowledge as is mine with those who are to follow.

I will apply, for the benefit of the sick, **all measures** which are required, avoiding those twin traps of overtreatment and therapeutic nihilism.

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.

I will not be ashamed to say "I know not," nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery.

I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God. I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.

I will prevent disease whenever I can, for prevention is preferable to cure.

I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm.

If I do not violate this oath, may I enjoy life and art, respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help.

[Written in 1964 by Louis Lasagna, Dean of the School of Medicine, Tufts University]

| Place of death 2011 | | |
|----------------------|--------|-------|
| | Total | Ň |
| Hospital | 39104 | 28,8 |
| Psychiatric hospital | 429 | 0,3 |
| Nursing home | 33411 | 24,6 |
| Care facility | 13097 | 9,6 |
| Other institution | 5447 | 4.0 |
| At home | 39234 | 28,9 |
| Elsewhere | 2246 | 1,7 |
| Unknown | 2773 | 2.0 |
| Total | 135741 | 100,0 |

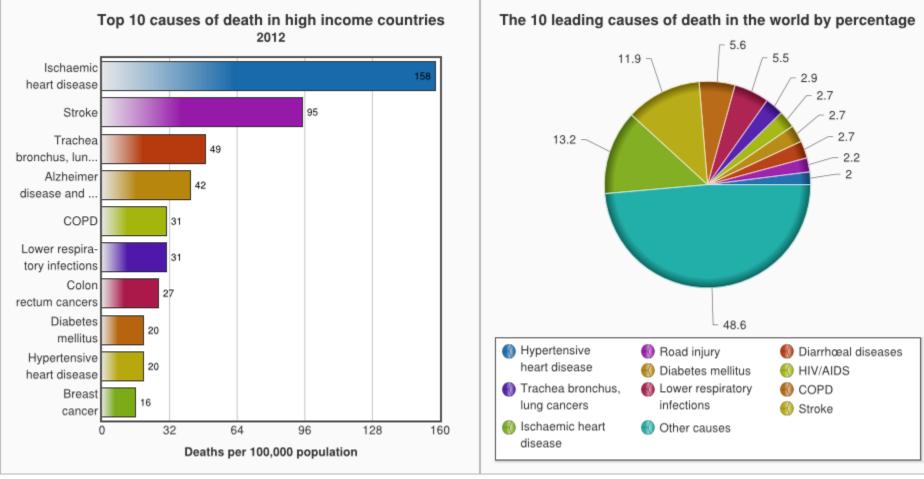
*



Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

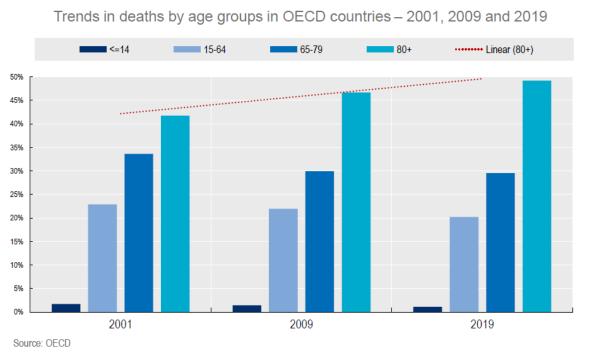
The correct bibliographic citation for the definition is:

Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.



retrieved 15 April 2015 from http://www.who.int/mediacentre/factsheets/fs310/en/

Older people represent a growing share in all deaths, and needs for end-of-life care are increasing



Organisation for Economic Co-operation and Development (OECD)

Total number people needing care will increase from 7 to 10 million

- **Organ failure** accounts for 41% of all deaths;
- **Terminal illnesses** (primarily cancer) for 25%;
- **Frailty** (mainly Alzheimer's disease and other dementias) for 21%.
- Frailty has been the fastest growing cause of death in the past two decades



Ageing and Dying Well

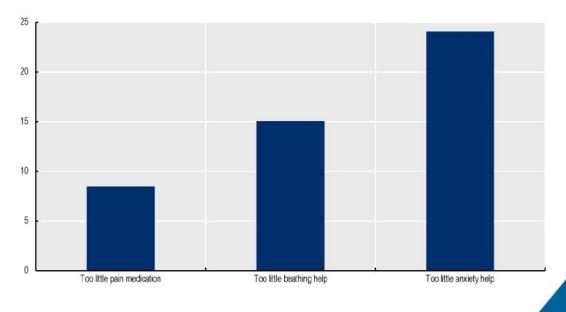
Care delivered does not always reflect the wishes of the patient and quality of care is poor

Less than 50% of older people have a document reporting their preferences of care or have defined a proxy person

40% of people visited the emergency department in the last 30 days of life

63% of countries have quality standards, but they are rarely binding and more than 1 in 4 countries do not have audit

Share of older people reporting receiving little help with symptoms at the end of life



Note: Data refer to people aged 65+ who had discussion with someone including family, a close friend or a healthcare professional. Source: (Commonwealth Fund, 2017).

Removing barriers to access care remains a priority

- **Only 40** % of people receive palliative care at the end of life
- While people prefer to die at home, half of deaths happen in hospitals



People with lower schooling are 50% less likely to receive end-of-life care services and more likely to have intensive life sustaining treatment

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Percentage of people using palliative care for the deceased at age 65 or over by country

Note: Weighted using cross-sectional weight from last core interview. Source: Waves 7-8 (2017-2020) of SHARE and Wave 14 (2018-2019) of HRS.

40%

Palliative Care

Care of the body, mind & spirit: Focusing on, social, emotional, cultural, spiritual & intellectual or knowledge aspects of care supported by an interdisciplinary team and training

> Holistic Approach

Lifethreatening & life-limiting illness

Life-threatening illness is an illness which could cause a patient to die (cancer, AIDS, old age, MND, terminal diabetes or heart disease) and life-limiting includes conditions which may compromise quality of life (spastic children, metabolic disorders, severe CVA)

Identification, impeccable assessment & treatment of symptoms

Patient-centred care incorporating respect for patients' values and preferences, provides information in clear and understandable terms, promotes autonomy in decision-making and attends to the need for physical comfort and emotional support.

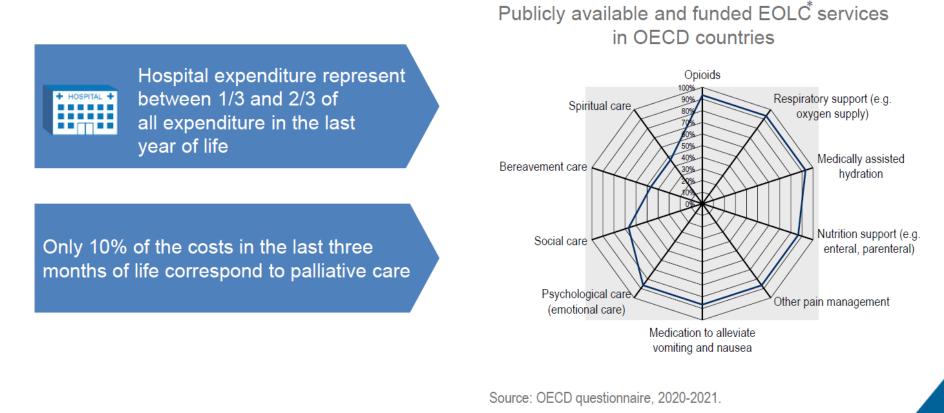
Quality of Life

Patients referred to DPH have an expectation of dying, therefore care of the families is included in the care i.e. Care of the infected and affected by the team while the patient is alive and into the bereavement period

Patients & families

Identification: knowledge & recognition of symptoms.; Impeccable Assessment: knowledge based professional evaluation; Treatment: Medication management, specialist referral, holistic intervention by Palliative Trained Team

Funding reveals coverage gaps and low incentives for non-hospital based palliative care



* EOLC = End Of Life Care



Enhancing care quality and making care more people-centred

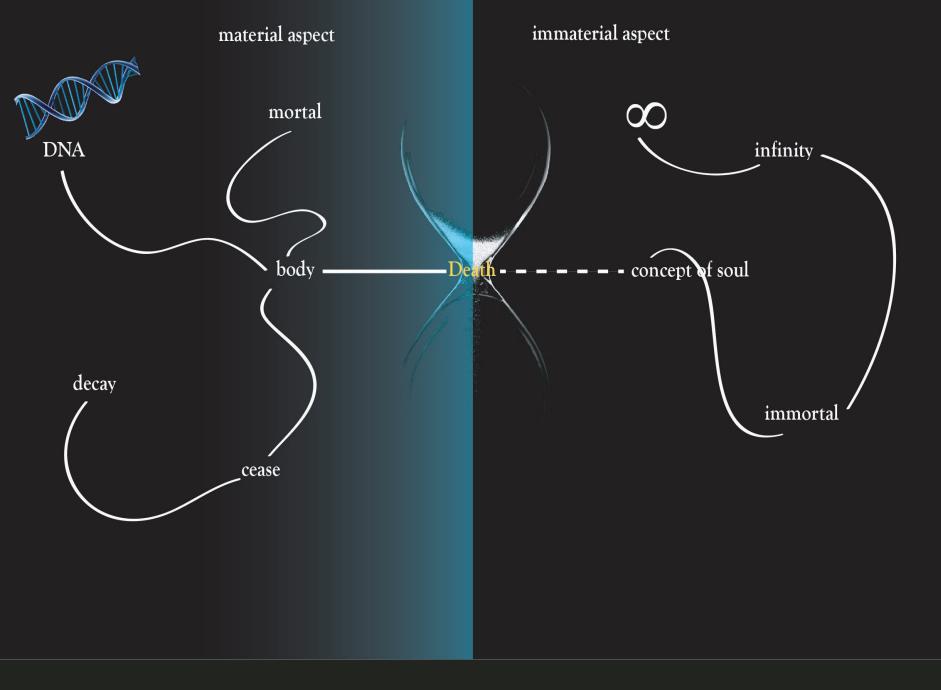
- Facilitate patient consultation and respect for patient wishes
- Promote appropriate symptom management
- Encourage multidisciplinary teams and training
- Generalise quality standards and audits

Improving timely access to care at the end of life

- Plan for and retain sufficient specialised professionals
- Develop services outside hospitals
- Promote screening mechanisms and targets for timely access

Promoting funding options for sustainable end-of-life care

- Modify payment systems to balance curative and palliative care
- Incentivise early palliative care outside hospitals
- Ensure sufficient support for family carers



Life that doesn't end with death

In Tana Toraja, weddings and births aren't the social gatherings that knit society together. In this part of *Indonesia*, big, raucous funerals form the center of social life. A look at this culture the bodies of dead relatives are cared for even years after they have passed. While it sounds strange to Western sensibilities, this could actually be a truer reflection of the fact that relationships with loved ones don't simply end when breathing does.

[from April 2013 at TEDMED 2013 http://www.ted.com/talks/kelli_swazey_life_that_doesn_t_end_with_death]



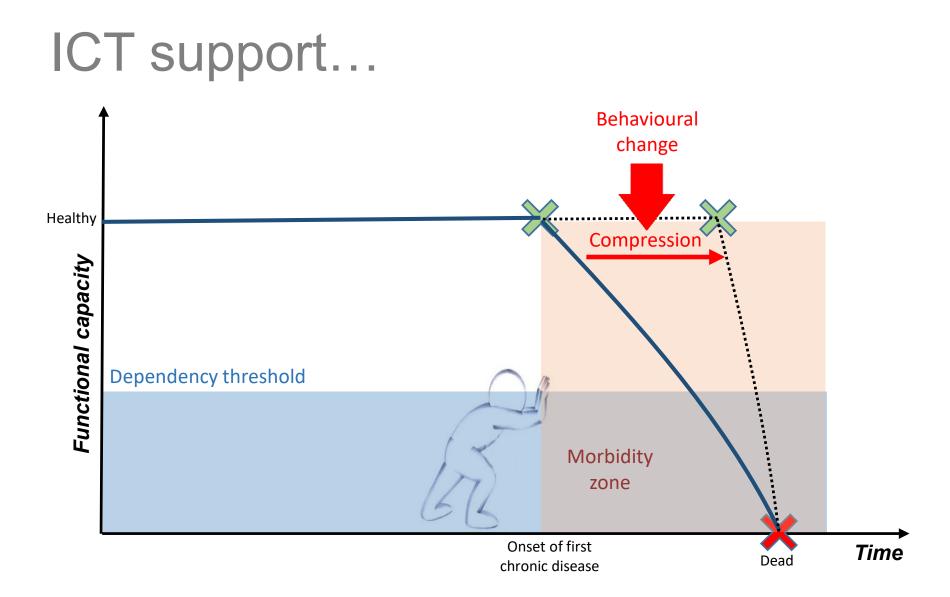
Kelli SWAZEY





DESIGN IS A PROCESS TO SOLVE CHALLENGES



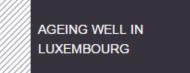


LUXEMBOURG CAPABILITIES IN ICT FOR AN AGEING POPULATION

TURNING INNOVATION INTO BUSINESS

☑ AGEING WELL IN LUXEMBOURG

- CLUSTER WORKING GROUP
- S COMPANIES
 - AAS (Ambient Activity Systems)
 - ACTIMAGE SA
 - · C-Services
 - Homesystem SA
 - Microsoft Luxembourg
 - MONITOR-it
 - Telindus Luxembourg
- □ PUBLIC RESEARCH
 - CRP Henri Tudor
 - Informatics, Systems, Collaboration (ISC)
 - Integrative Research Unit on Social and Individual Development (INSIDE)
 - Interdisciplinary Centre for Security, Reliability and Trust (SnT)
- □ USER ORGANISATION
 - SECHER DOHEEM



Luxembourg may be a small country but its potential for research and innovation is high. Boosting ICT as an enabling technology in order to tackle the challenge of an ageing population, to enhance independent living and improve the quality of life of elderly people is a key priority for the Luxembourg ICT R&D community.

Why Luxembourg?

Luxembourg offers a wide range of competitive advantages, making the country a particularly attractive location for the development, testing and the market launch of innovative ICT solutions for an ageing population.

- With its strategic geographical location and its multicultural society, Luxembourg is an ideal location to develop, test and launch innovative solutions taking into account the diversity of the European population.
- Luxembourg offers powerful, hightech ICT infrastructures and fibre networks (e.g. data centres, public wifi hotspots) and holds a leading position in Europe in terms of internet adoption.
- The Luxembourg players, including technology-friendly healthcare organisations, research actors, i.e. the University of Luxembourg
 as well as various public research centres, technology providers and integrators are ready to respond to the needs and
 requirements of elderly people.
- Luxembourg presents a dynamic research community as well as many young and innovative enterprises who often collaborate in Public-Private-Partnerships. Following a pro-active and interdisciplinary economic development policy, Luxembourg supports innovation and research with a strong focus on both ICT and healthcare technologies.
- Luxembourg offers a rewarding business environment, including Governmental support for collaborative development projects and funding for innovative products and services.







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Web based tool - How to Make Preparations for a Funeral

[http://www.wikihow.com/Make-Preparations-for-a-Funeral]

1-Choose a funeral home.



2-Call your pastor, rabbi, spiritual leader to help you set up at your place of worship for a service.



3-Ask friends and loved ones to bring pictures of the deceased to make photo collages.



4-Also have a photo to give to the funeral director for reference.



5-Consider asking for donations instead of or as well as flowers.



6-Leave a guest book at the wake and funeral so that people can leave their addresses if they wish.



& 2 more steps ...

[pictures taken from http://www.eng.nus.edu.sg/ero/news/index.php?id=911 https://khooet.wordpress.com/confucius-computer/ http://mixedrealitylab.org/projects/all-projects/confucius-computer/

Confucius Computer

Transforming the Future through Ancient Philosophy

CONFUCIUS COMPUTER



Online Chat



Cooking/Diet

Music Appreciation

Confucius Music-painting: Interaction Mode





benevolent, cause superior, dismissal upright complaisant ease is a virtuous dwelling.







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Body state: Your body state is hot:

Mooncake skin: Suzhou style (warm)

Fillings: Filling 1: Deer (hot) Filling 2: Black fungus (cool) Filling 3: Ginseng (warm)

Yin-yang value of mooncake:

Warm

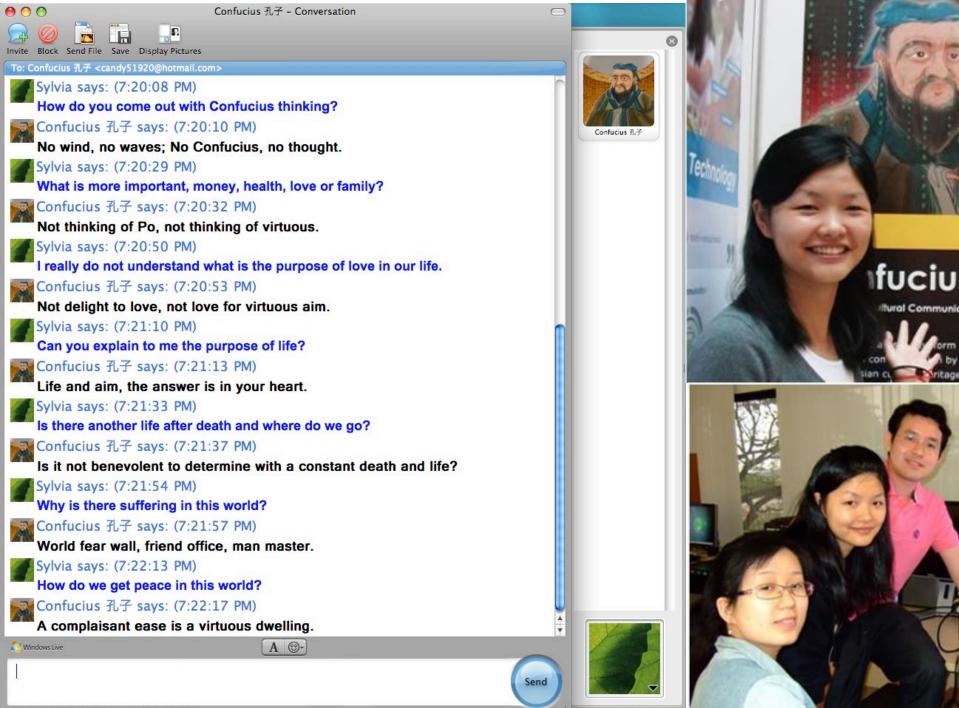




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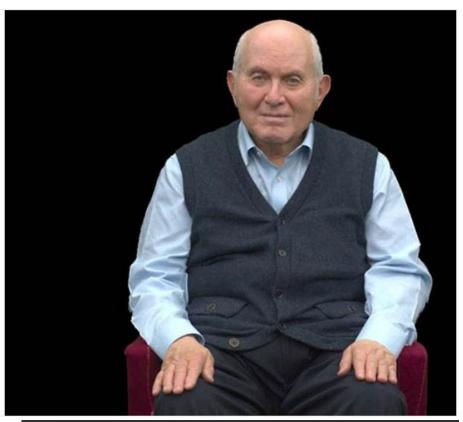
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Dimensions in Testimony Available in IWitness

Meet Pinchas Gutter

Through Dimensions in Testimony, students and educators can ask questions that prompt real-time responses from a prerecorded video of Pinchas—engaging in virtual conversation, redefining inquiry-based education.

Integration in IWitness is made possible through the generous support of The Snider Foundation.

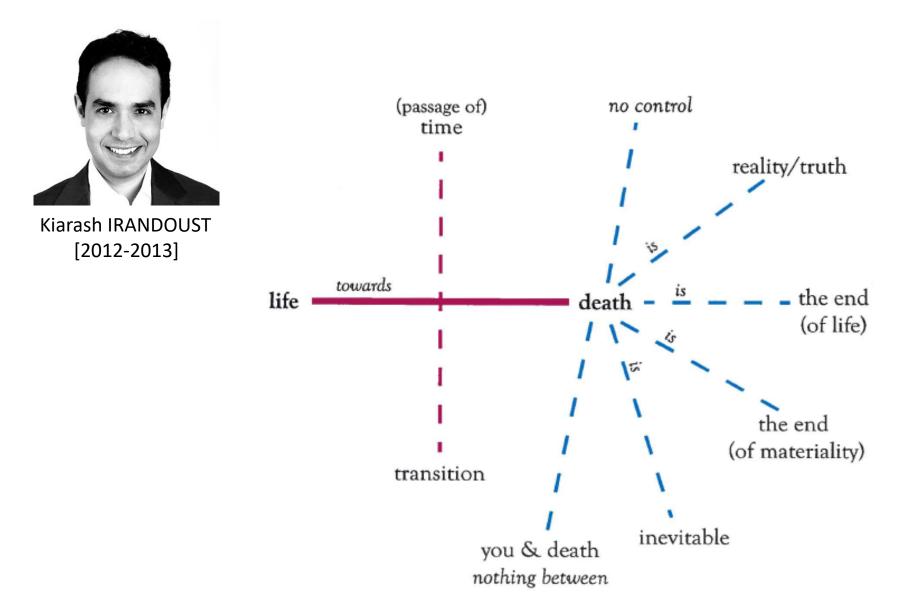


SPEAK WITH PINCHAS AT IWITNESS

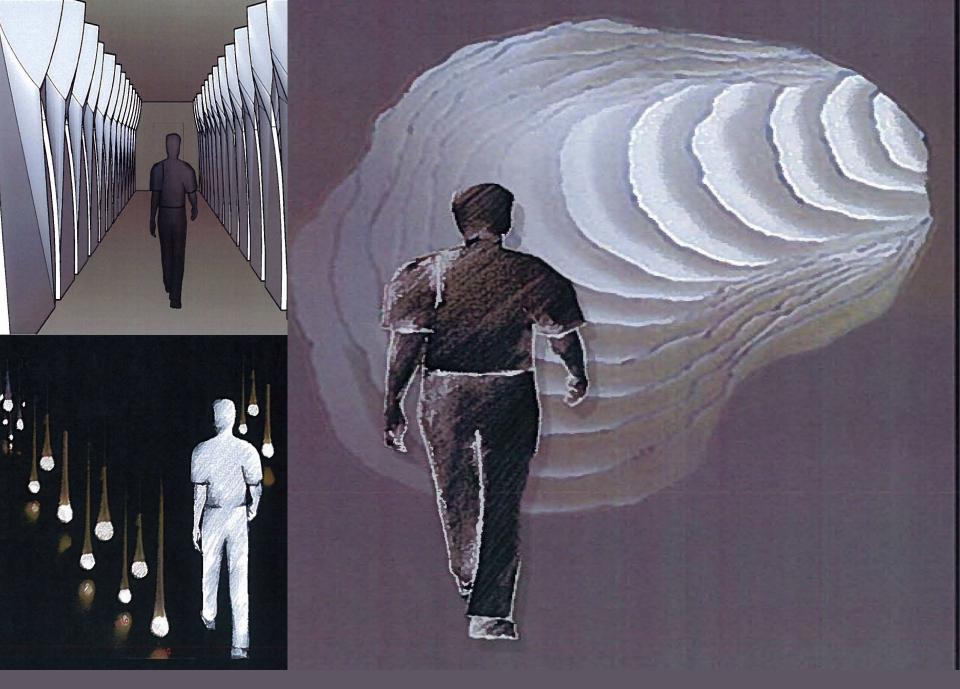




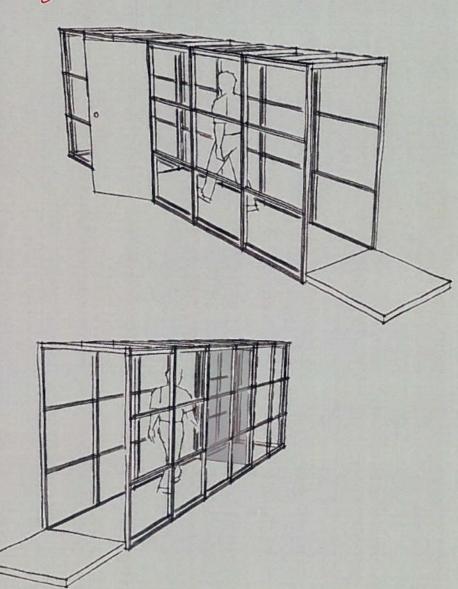
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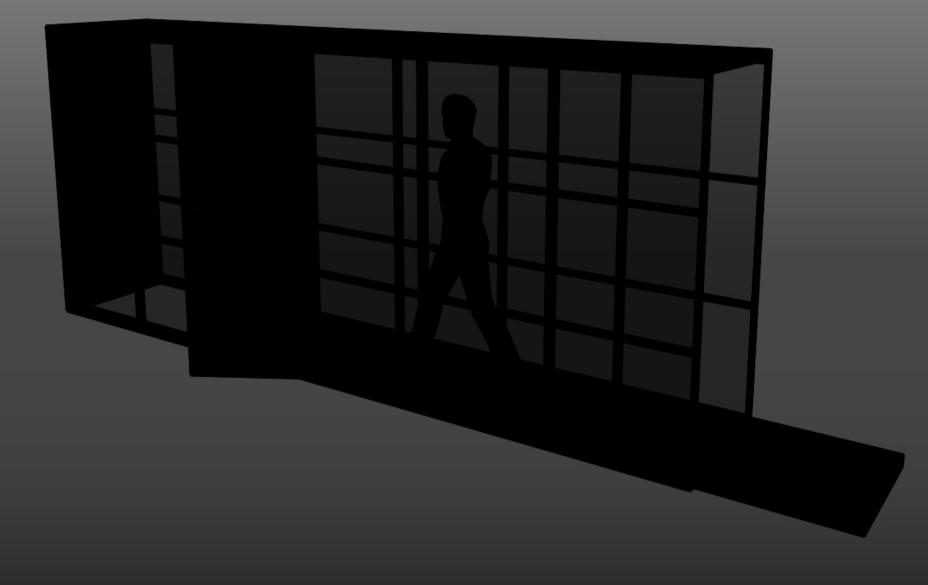
REF: https://rauterberg.employee.id.tue.nl/lecturenotes/2013-PoL-death_stage-small.pdf



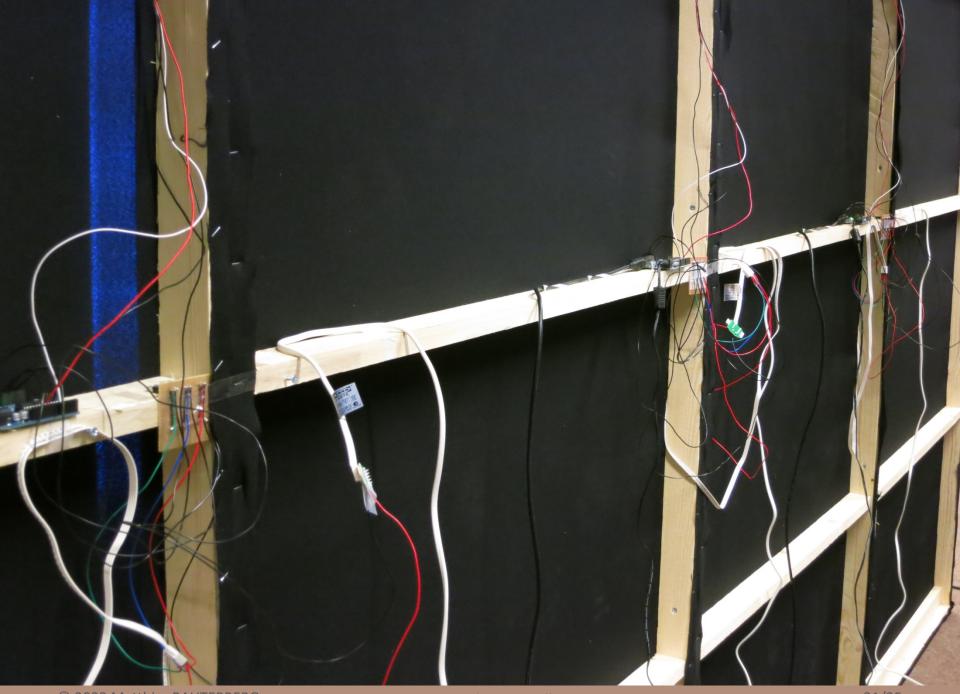
Realization















@ The end. the tunnel of life.

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Aubrey de Grey: A roadmap to end aging. http://www.ted.com/talks/aubrey_de_grey_says_we_can_avoid_aging



Jane Fonda: Life's third act. http://www.ted.com/talks/jane_fonda_life_s_third_act



Judy MacDonald Johnston: Prepare for a good end of life. http://www.ted.com/talks/judy_macdonald_johnston_prepare_for_a_good_end_of_life



Peter Saul: Let's talk about dying. http://www.ted.com/talks/peter_saul_let_s_talk_about_dying



Alison Killing: There's a better way to die, and architecture can help. http://www.ted.com/talks/alison_killing_there_s_a_better_way_to_die_and_architecture_can_help



Kelli Swazey: Life that doesn't end with death. http://www.ted.com/talks/kelli_swazey_life_that_doesn_t_end_with_death

Thank you very much!