

Dying Well

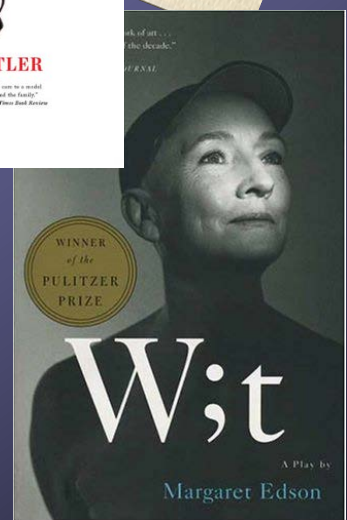
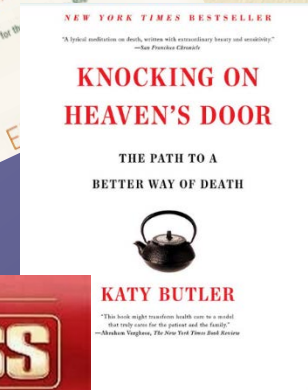
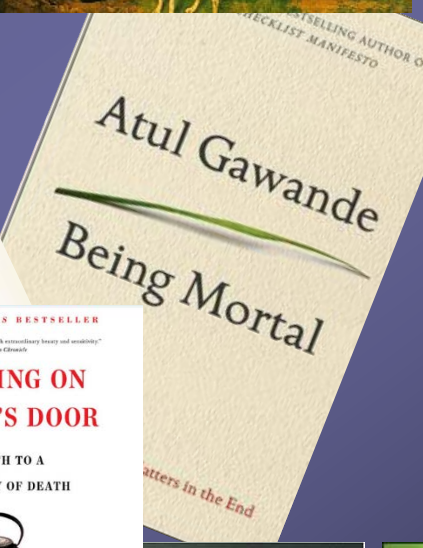
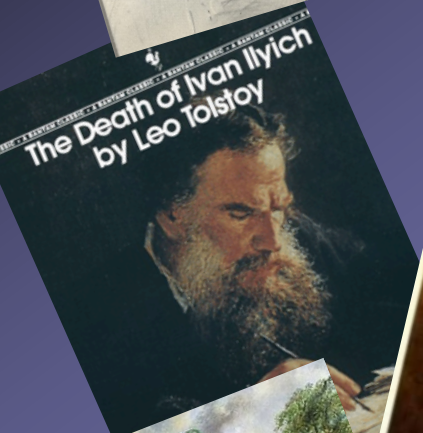
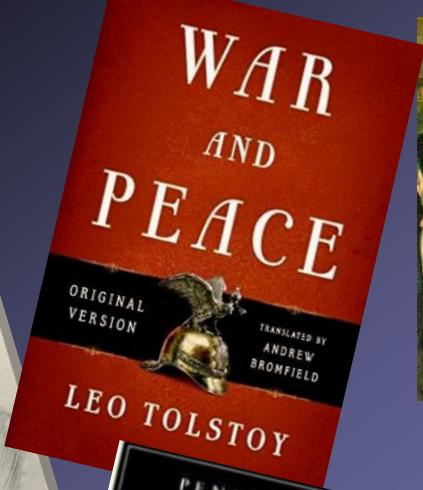
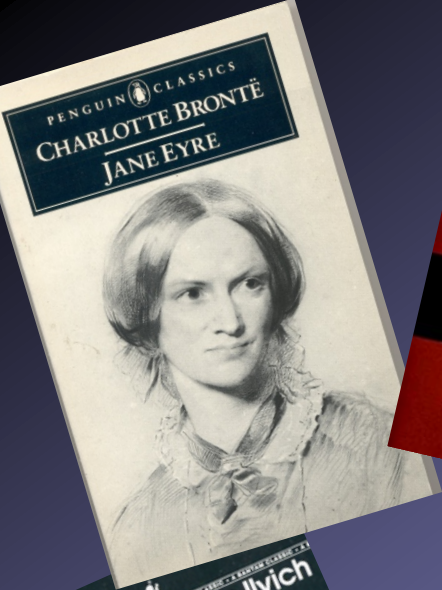
Robert Macauley, MD

Medical Director of Clinical Ethics,
University of Vermont Medical Center

Professor of Pediatrics, UVM College of Medicine

Where we'll go over the next hour

- Explore what we think a “good death” really means
- Examine what death used to look like, and what it looks like now
- Identify ways to help our patients—and ourselves—achieve a good death

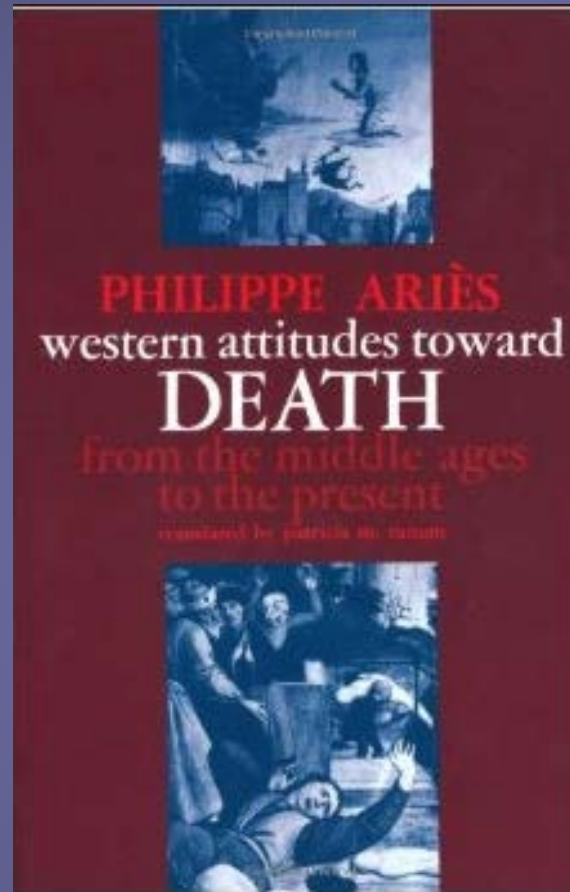


So what do we think?

Good death

Bad death

How we view death has changed



Western Attitudes Toward Death

Philippe Ariès (1974)

- Tamed Death (before 1000 CE)
- One's Own Death (11th to 17th centuries)
- Beautiful Death (18th to early 19th centuries)
- Forbidden Death (late 19th cent. to present)

Tamed Death

- People knew death was coming and prepared for it
 - Lie down
 - “The dying man must lie on his back so that his face is always turned toward heaven.” -- Guillaume Durand, Bishop of Mende
 - Prayer to God: confession and plea
 - Wait for death
 - *Mors improvisa* (sudden death) was the worst kind of death
- Public ceremony
 - Pre-18th century: no portrayal of deathbed scene that didn't include children
 - 19th century: processions still formed following priest bringing the last sacrament
- No great show of emotion

Song of Roland (11th century)

Roland feeleth his hour at hand;

On a knoll he lies towards the Spanish land.

With one hand beats he upon his breast:

“In thy sight, O God, be my sins confessed.

From my hour of birth, both the great and small,

Down to this day, I repent of all.”

As his glove he raises to God on high,

Angels of heaven descend him nigh.

Then drooped his head upon his breast,

And with clasped hands he went to rest.



One's Own Death

11th to 17th centuries

- Before 1000 CE
 - Collective notion of destiny
 - Artistic depictions of divine welcome after death
- Beginning 11th century
 - Each person is judged individually
 - Moments before death are final test/temptation
 - *Ars moriendi* (~1460)

The Afterlife

... The dread of something after death,
The undiscovered country, from whose bourn
No traveler returns, puzzles the will
And makes us rather bear those ills we have
Than fly to others we know not of.

William Shakespeare
Hamlet, Act III, Scene 1

"Death of the Miser"

Hieronymus Bosch (1490)



Deaths' Duell

John Donne's final sermon (1631)

That which we call life, is but ... a week of deaths, seven days, seven periods of our life spent in dying, a dying seven times over; and there is an end. Our birth dies in infancy, and our infancy dies in youth, and youth and the rest die in age, and age also dies, and determines all.

“That no man should be called
happy until after his death”

Michel de Montaigne (16th century)

In this last scene between ourselves and death, there is no more pretense. We must use plain words, and display such goodness or purity as we have at the bottom of the pot.

One of the principal aims of my life is to conduct myself well when it ends -- peacefully, I mean, and with a calm mind.

The Age of the Beautiful Death

18th to early 19th centuries

- Death as joyous transition
- Emotional response to death of others
- Beginning to question heaven and hell
 - Less emphasis on clergy
 - More trust in physicians, even though they can't really do anything

Jane Eyre

Charlotte Brontë (1846)

"I am very happy, Jane; and when you hear that I am dead, you must be sure and not grieve: there is nothing to grieve about. We all must die one day, and the illness which is removing me is not painful; it is gentle and gradual; my mind is at rest ... By dying young, I shall escape great suffering. I had not qualities or talents to make my way very well in the world: I should have been continually at fault."

War and Peace

Leo Tolstoy (1869)

“Yes, it was death! I died – and woke up. Yes, death is an awakening!” And all at once it grew light in his soul and the veil that had till then concealed the unknown was lifted from his spiritual vision. He felt as if powers till then confined within him had been liberated, and that strange lightness did not again leave him.

"The Burial at Ornans"

Gustave Courbet (1849)

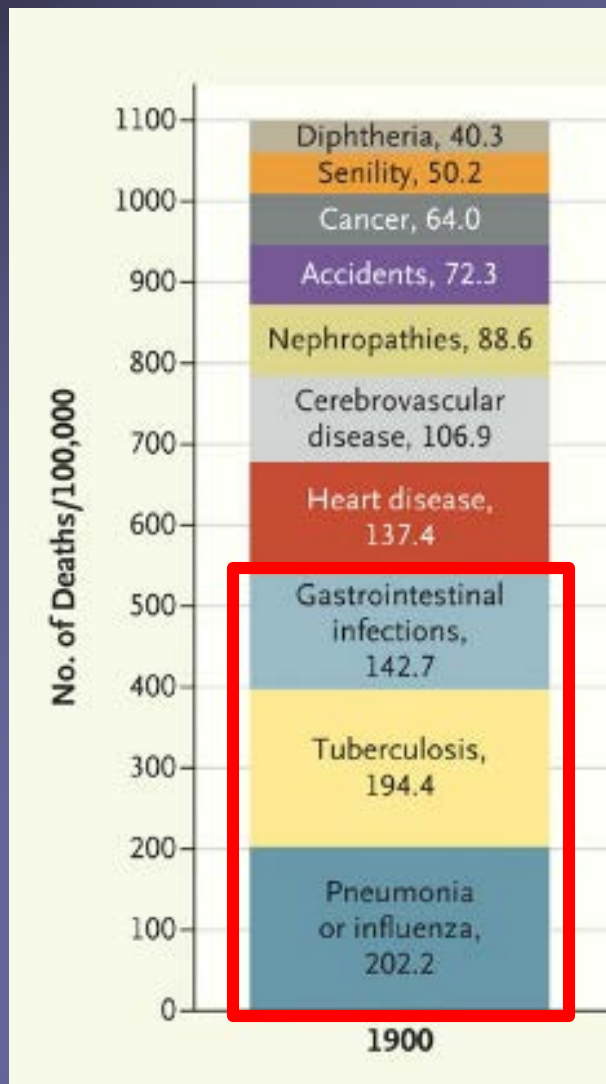


Forbidden Death

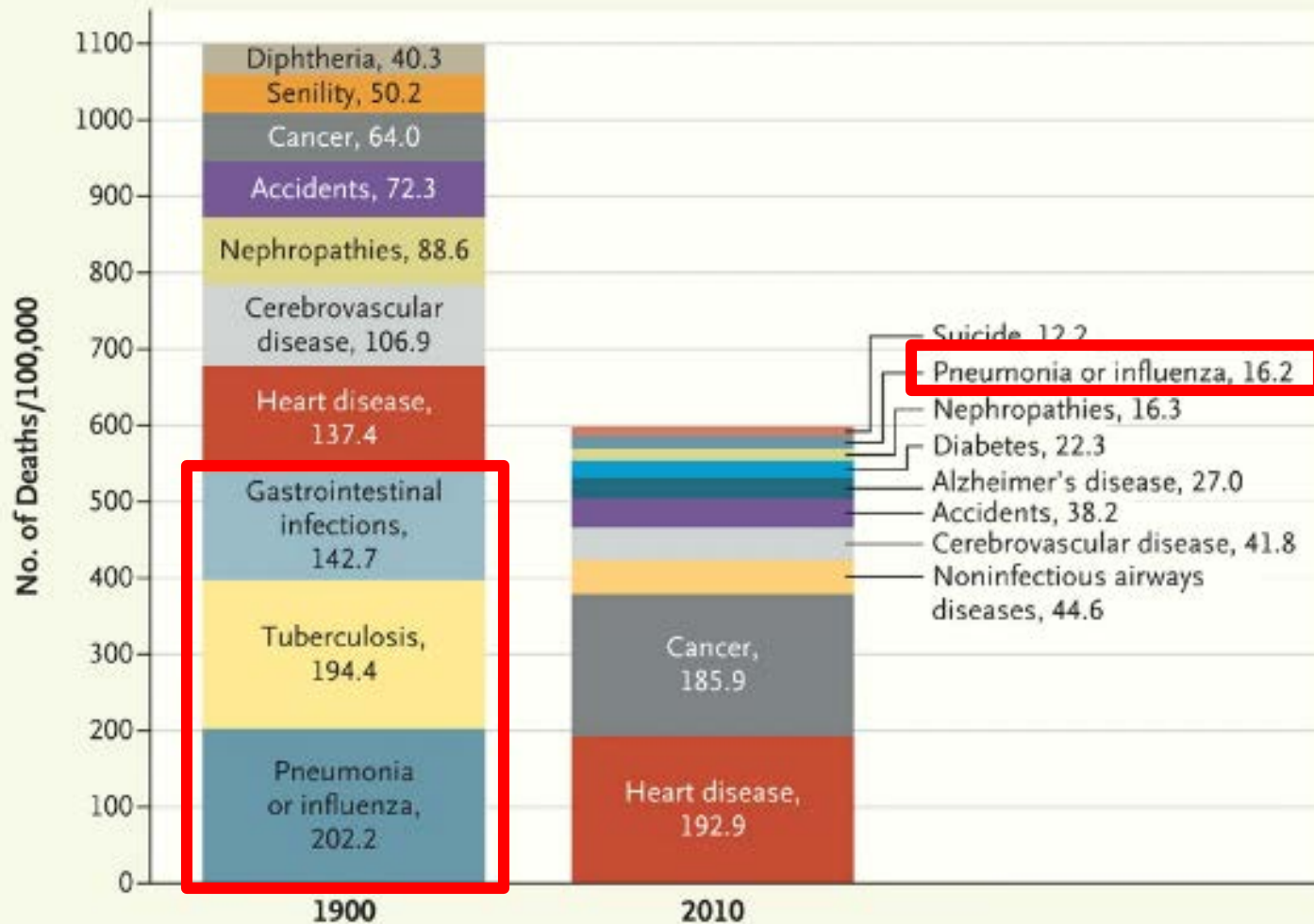
From second half of 19th century

- Concealment of death
 - Don't tell the patient how sick they are
 - Cremation becomes more common
- Death as dirty
 - Not just the disease: also the patient
- Medicalization of death
 - Lengthening of death, especially in hospitals
 - Decreased emotion in technical setting
 - *Mors improvisa* is the best kind of death

Causes of death



Causes of death



Concealment of Death

"The Death of Ivan Ilyich," Leo Tolstoy (1886)

Ivan Ilyich's chief torment was a lie, -- the lie somehow accepted by everyone, that he was only sick, but not dying, and that he needed only to be calm, and trust to the doctors, and then somehow he would come out all right. But he knew that, whatever was done, nothing would come of it, except still more excruciating anguish and death.

"The Death of Ivan Ilyich" (cont'd)

This lie, this lie, it clung to him, even to the very evening of his death; this lie, tending to reduce the strange, solemn act of his death to the same level as visits, curtains, sturgeon for dinner – it was terribly painful for Ivan Ilyich. And strange! many times, when they were playing this farce for his benefit, he was within a hair's breadth of shouting at them:

"Stop your foolish lies! you know as well as I know that I am dying, and so at least stop lying."

But he never had to the spirit to do this.

Dirtiness of Death

Madame Bovary, Gustave Flaubert (1857)

Drops of sweat ran down her bluish face ..., her teeth chattered, her enlarged eyes stared vaguely into space ... Little by little her groans became louder. A muffled scream escaped her ... Her lips were drawn, her limbs contracted, her body was covered with brown spots, and her pulse eluded his fingers. Then she began to scream horribly ... with her chin against her chest, Emma opened her eyes very wide, and her poor hands plucked at the sheets with that hideous and pathetic gesture of the dying, who seem to want to wrap themselves already in their shroud ... Her chest began to heave rapidly. Her whole tongue protruded from her mouth; her rolling eyes grew as dim as two lamp globes being extinguished.

Medicalization of Death

A story

Sitting at home on a Friday night

- With my four kids, including an infant
- Call from OB
 - Woman at 22 weeks gestation
 - Ruptured membranes
 - Triplets
- Wants “everything” done
- Three resuscitation tables set up in O.R.

What have I got to lose?

If we treat, they might live.

If we don't treat, they have no chance.

What he imagined/hoped for



Implicit assumptions

- Not treating for survival = not treating
- You don't lose anything by trying.
- Dying is dying.

What really lay ahead



Outcomes	Outcomes for All Infants	Outcomes for Mechanically Ventilated Infants
Survival	5%	9%
Survival Without Profound Neurodevelopmental Impairment	3%	4%
Survival Without Moderate to Severe Neurodevelopmental Impairment	1%	2%
Death	95%	91%
Death or Profound Neurodevelopmental Impairment	97%	96%
Death or Moderate to Severe Neurodevelopmental Impairment	99%	98%

If we focus on survival,
the babies will die in an ICU,
with lots of tubes, receiving CPR.

If we focus on comfort, you'll be able
to hold them for their entire lives.

JOURNAL OF PALLIATIVE MEDICINE
Volume 18, Number 2, 2015
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DOI: 10.1089/jpm.2014.0262

Turn of Phrase

Robert Macauley, MD, FAAP, FAAHPM

WHEN I GOT HOME on that winter night I thought my work was done. Judging from the hysterical giggling and sound of slamming doors, all four of my kids were up-

“Let me put it this way: I’m standing in the operating room looking at three neonatal teams each prepping their own warming table.”

(Macauley, 2015)

home

Premature birth
The Observer

'Nathan was born at 23 weeks. If I'd known then what I do now, I'd have wanted him to die in my arms'

Alexia Pearce adores her 'gorgeous' three-year-old son, yet she is aware that his life - a life blighted by cerebral palsy and chronic lung disease - is unlikely to last long into his teens. In this moving account, she asks: are we always right to save premature babies?

I had cancer while I was pregnant



< 74,470

Tracy McVeigh

Saturday 19 March 2011 20:03 EDT



Alexia Pearce and her son Nathan, three, who was born premature, photographed at their home in Petersfield. Photograph: Katherine Down for the Guardian

Advertisement



"Solitude"

Laugh, and the world laughs with you,

Weep, and you weep alone...

Succeed and give, and [the world] helps you live,

But no man can help you die.

Ella Wheeler Wilcox (1850-1919)

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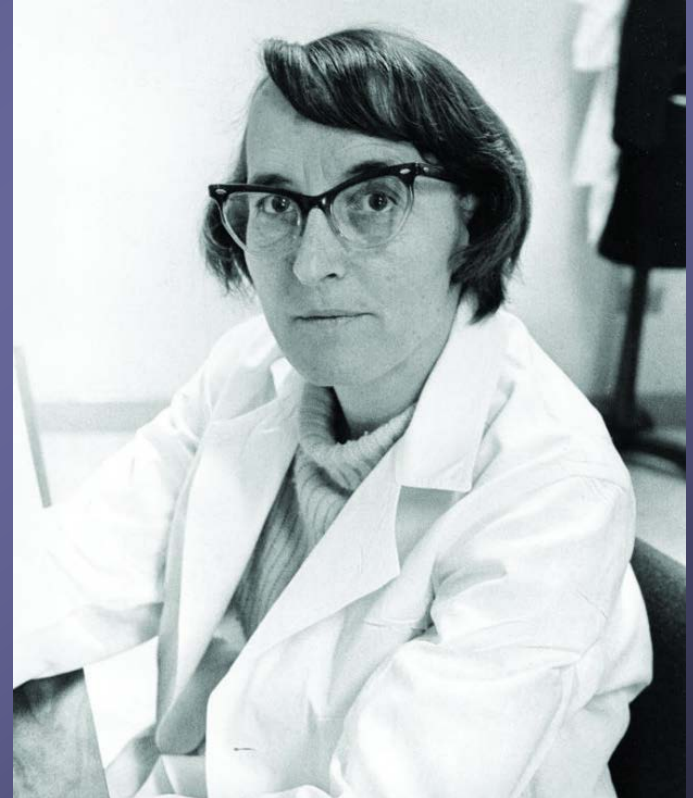
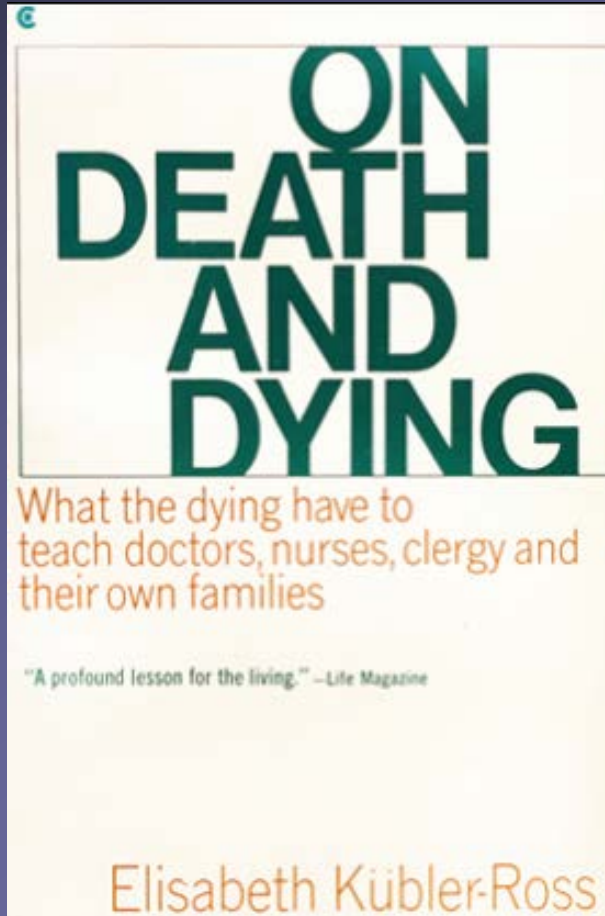
But no man can help you die.

Ella Wheeler Wilcox (1850-1919)

But the pendulum is swinging back

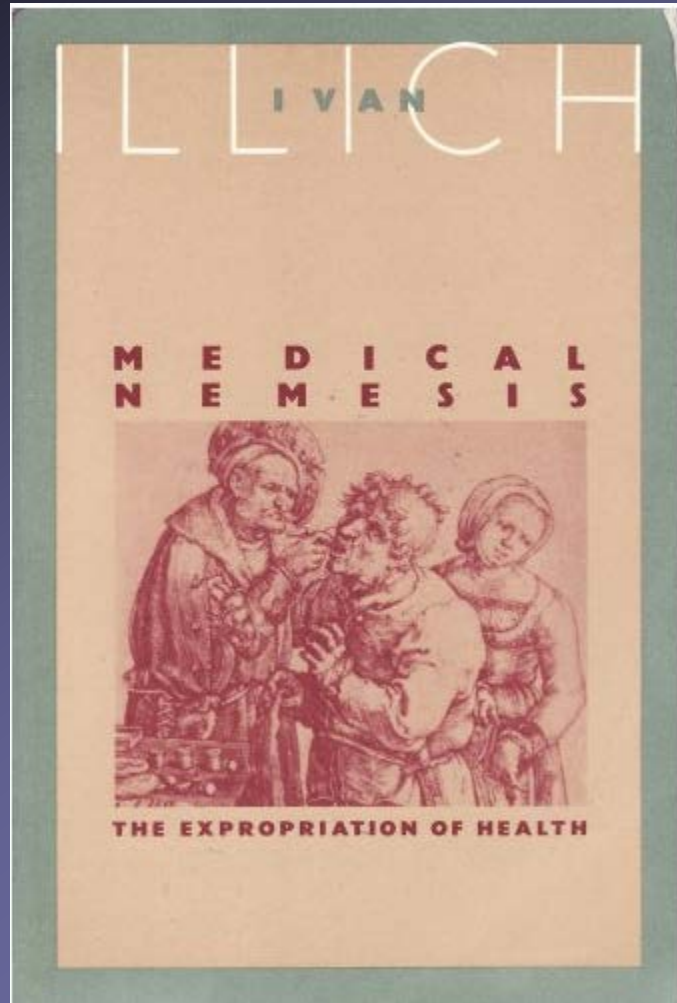
And we're beginning to talk about
death again

Forces of change





Predictions are coming true



“By working creatively, and in ways yet unthought of, the lobby of the dying and the gravely ill could become a healing force in society.”
(1982)

The Social Programme at St Christopher's



Changing attitudes towards death and dying
Join us at one of our regular weekly events open to all



All social events open to patients, carers, family, friends, staff, volunteers and the general public at The Anniversary Centre

Thursdays

EVERY THURSDAY

7-9pm

NEW Death Chat at St Christopher's

HELP BREAK TABOOS AROUND DEATH AND DYING

Talking about death and dying remains one of the biggest taboos within most communities. Experience shows that talking about death and dying in the company of others can help to alleviate fears or concerns and enhance our quality of daily life. We know that in order to help with any anxieties we have about death and dying, it makes a difference when we are able to discuss things openly and to make our wishes known in advance.

Death Chat provides an opportunity to meet and talk with others about death and dying. Over an evening's conversation, there will be the opportunity to discuss what you think and feel and to make your own wishes known.

These conversations will be facilitated by an experienced member of staff from the hospice team. Join us to break taboos and hopefully to have some fun along the way!

Cheese and wine are available at a reasonable price.



Select Language

Search

Welcome to Death Cafe

At Death Cafes people drink tea, eat cake and discuss death. Our aim is to increase awareness of death to help people make the most of their (finite) lives.

Read more



Find your nearest Death Cafe:

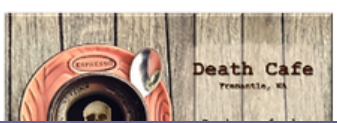
Search

Stay tuned for our plans to open a real Death Cafe in London!

Recent posts

Death Cafe: Death Cafe - Fremantle, WA

Posted by [avareyerson](#) on May 30, 2014, 9:09 a.m.



With Ava Reyerson

June 14, 2014, 1.00 p.m. - 3.00 p.m. (GMT+8 Perth)

Free (food and drink of choice to be paid for at the counter)

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DEATH CAFE

*You know you've
wondered about it!*

*You know you're curious
about what others think!*

*Come join us for an
informal sharing of
thoughts, questions and
concerns about any aspect
of grieving, dying and
death.*

*Facilitated by **Peg Lorenz,**
Home Funeral Educator &
Trish Garrigan, Hospice
Volunteer*

*Learn more at
www.DeathCafe.com*

Death Café is an international movement started in Europe dedicated to taking death out of the closet and discussing it publicly — to increase awareness of death with a view to help people make the most of their (finite) lives.

It's not a support group, or a counseling session, not even a workshop...but simply community members coming together in a relaxed, comfortable atmosphere, sipping tea or coffee, munching treats and sharing respectful, engaging, thought provoking and life affirming conversation.

People around the world are discussing: What happens after death? How do I help my parents when they're approaching end of life? How can we prepare for our own death? How does thinking about death improve my life? Differences in grieving rituals. Near death experiences. What is a green burial? And much, much more!

Wednesday, March 26 | 7:00PM**R.H.L. - Couper Room****Everyone welcome!****Register Online @ littletonlibrary.org**



NEW YORK TIMES BESTSELLING AUTHOR OF
THE CHECKLIST MANIFESTO

Atul Gawande



Being Mortal

Medicine and What Matters in the End

"Solitude"

There is room in the halls of pleasure
For a long and lordly train,
But one by one we must all file on
Through the narrow aisles of pain.

"Solitude," by Ella Wheeler Wilcox (1850-1919)

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NEW YORK TIMES BESTSELLER

"A lyrical meditation on death, written with extraordinary beauty and sensitivity."
—*San Francisco Chronicle*

KNOCKING ON HEAVEN'S DOOR

**THE PATH TO A
BETTER WAY OF DEATH**



KATY BUTLER

"This book might transform health care to a model
that truly cares for the patient and the family."
—Abraham Verghese, *The New York Times Book Review*



Tintern Abbey



Tintern Abbey



William Wordsworth,

"Lines Composed a Few Miles Above Tintern Abbey (1798)

...These beauteous forms,
Through a long absence, have not been to me
As is a landscape to a blind man's eye:
But oft, in lonely rooms, and 'mid the din,
Of towns and cities, I have owed to them
In hours of weariness, sensations sweet,
Felt in the blood, and felt along the heart;
And passing even into my purer mind,
With tranquil restoration: —feelings too
Of unremembered pleasure: such, perhaps,
As have no slight or trivial influence
On that best portion of a good man's life...



"A Gothic skeleton, soaring and roofless, in a green hilly landscape. Grass grows in the transept. The vanished roof lets in light. The delicate stone tracery of its slim, arched quatrefoil windows opens onto green pastures where black-and-white cows graze. Its shape is beautiful, formal, and mysterious."

Katy Butler,
Knocking on Heaven's Door



“After he developed dementia, my father was no longer useful to anybody. But in the shelter of his broken walls, my mother learned to balance her checkbook, and my heart melted and opened. Never would I wish upon my father the misery of his final years. But he was sacred in his ruin, and I took from it the shards that still sustain me.”

Katy Butler,
Knocking on Heaven's Door

Dying is not an emergency. Emergency rooms, 911 systems, and ICUs are all primed to prevent natural death. Engage them with caution. **The most important sentences in this book may be, "I request a palliative care consult," "Can you refer me to hospice?" "I request comfort measures only," and "I am concerned about quality of life."**

Katy Butler, Knocking on Heaven's Door

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"This remarkable book ... illustrates how the medical community and society can 'make the best of what is often the very worst time of life.' An absorbing read."
—*The Wall Street Journal*

**A PHYSICIAN'S QUEST
TO TRANSFORM CARE
THROUGH THE END OF LIFE**

The Best Care Possible



IRA BYOCK, MD
author of *Dying Well*

THE NEW YORKER

ANNALS OF MEDICINE

LETTING GO

by Atul Gawande

AUGUST 2, 2010

What should medicine do when it can't save your life?

RHL

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Everyone welcome!

Register Online @ littletonlibrary.org



Good to Go

*A Guide to Preparing
for the End of Life*

A Is For Attitude • Caregivers Have Feelings, Too
Etiquette Of Sympathy And Grief • Let's Put The
Fun Back In Funeral • Dying While Doing Some-
thing You Love • Independence Issues • If You
Love Your Loved Ones, Pre-Plan • Presenting Items
To People Before You Go • The Will: Write It Down

Jo Myers

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,
Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H.,
Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N.,
Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,
J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

On first encounter with palliative care

“Finally we were not alone.”

Katy Butler, *Knocking on Heaven's Door*

So how do we die well, and
help others do so, too?

Plan ahead

- Document your preferences
 - Advance Directive
 - “Five Wishes”
- Talk to the people who love you
- Tell them what’s in your heart
 - And how much you want them to listen to their own
- Keep taking care of them, even after you’re gone

DON'T PANIC - IT'S OK

Written during an early Conversation Project meeting
by Karen Boudreau, MD, Senior Vice President, IHI
Letter to her Family

Don't Panic - it's ok

If you are faced with a decision that
you're not ready for, it's ok

I'll try to let you know what I would want
for various circumstances, but if you
come to something we haven't anticipated,
it's ok

And if you come to a decision point and
what you decide results in my death,
it's ok. You don't need to worry
that you've caused my death - you
haven't - I will die because of
my illness or my body failing or
whatever. You don't need to feel
responsible.

Forgiveness is not required, but
if you feel bad/responsible/guilty, first
of all don't and second of all, you
are loved and forgiven.

If you're faced with a snap decision don't panic -
Choose comfort, choose home, choose
~~the~~ less intervention, choose to be together,
at my side, holding my hand, singing,
laughing, loving, celebrating, and
carrying on. I will keep loving you
and watching you and being proud of
you. ~ Kambojwani

Question the assumptions

- Treating for comfort is just as intensive as treating for survival.
- There's no perfect plan.
- There are better (and worse) ways to die.
 - And it's different for everyone.

The things that matter most

1. Please forgive me.
2. I forgive you.
3. Thank you.
4. I love you.
5. (Goodbye.)

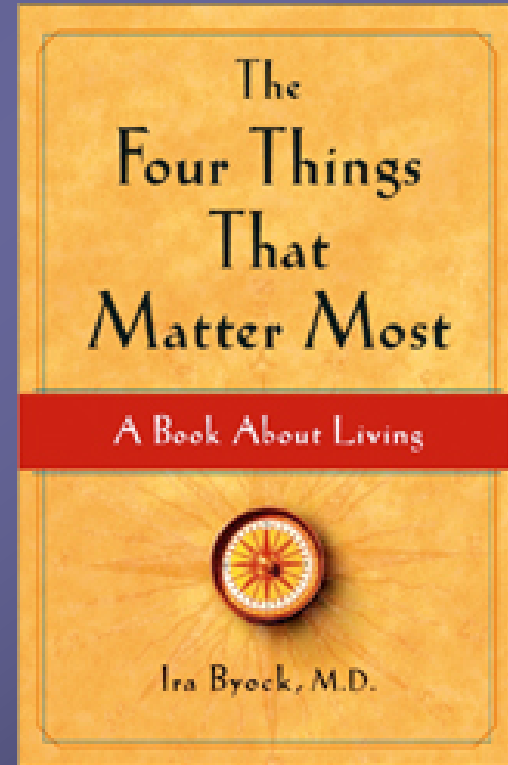


Table 2. Attributes Rated as Important by More Than 70% of All Participants

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %			
	Patients (n = 340)	Bereaved Family Members (n = 332)	Physicians (n = 361)	Other Care Providers (n = 429)
Be kept clean	99	99	99	99
Name a decision maker	98	98	98	99
Have a nurse with whom one feels comfortable	97	98	91	98
Know what to expect about one's physical condition	96	93	88	94
Have someone who will listen	95	98	99	99
Maintain one's dignity	95	98	99	99
Trust one's physician	94	97	99	97
Have financial affairs in order	94	94	91	90
Be free of pain	93	95	99	97
Maintain sense of humor	93	87	79	85
Say goodbye to important people	90	92	95	99
Be free of shortness of breath	90	87	93	87
Be free of anxiety	90	91	90	90
Have physician with whom one can discuss fears	90	91	94	93
Have physician who knows one as a whole person	88	92	92	95
Resolve unfinished business with family or friends	86	85	87	97
Have physical touch	86	94	90	97
Know that one's physician is comfortable talking about death and dying	86	85	93	97
Share time with close friends	85	91	91	96
Believe family is prepared for one's death	85	88	83	90
Feel prepared to die	84	81	79	87
Presence of family	81	95	95	96
Treatment preferences in writing	81	85	73	90
Not die alone	75	93	84	88
Remember personal accomplishments	74	80	78	91
Receive care from personal physician	73	77	82	82

We agree on a lot of things about a good death

(Steinhauser, Christakis et al. 2000)

But we also disagree (with our doctors)

Table 3. Attributes Rated as Important by More Than 70% of Patients But Not Physicians*

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %	
	Patients	Physicians
Be mentally aware	92	65
Be at peace with God	89	65
Not be a burden to family	89	58
Be able to help others	88	44
Pray	85	55
Have funeral arrangements planned	82	58
Not be a burden to society	81	44
Feel one's life is complete	80	68

* $P < .001$ for all comparisons.

(Steinhauser, Christakis et al. 2000)

Acknowledge our own mortality

- How it affects our decision-making
- How it enables us to empathize
- How it burdens us as we keep going

Dying is hard on the dying.
Death is hard on the living.

Katy Butler, Knocking on Heaven's Door

A story of Grace



YOU ARE NOW LEAVING OZ.



References

- Ariès, P. (1974). Western attitudes toward death: from the Middle Ages to the present. Baltimore, Johns Hopkins University Press.
- Butler, K. (2013). Knocking on heaven's door : the path to a better way of death. New York, Scribner.
- Macauley, R. (2015). "Turn of phrase." J Palliat Med **18**(2): 197-199
- Steinhauser, K. E., et al. (2000). "Factors considered important at the end of life by patients, family, physicians, and other care providers." JAMA **284**(19): 2476-2482.