Euthanasia and Assisted Suicide: Speaking from the Evidence

Margaret Cottle, MD
Vancouver, BC, Canada

“In the tender compassion of our God
    The dawn from on high shall break upon us,
    To shine on those who dwell in darkness and the shadow of death
    And to guide our feet into the way of peace.”

Song of Zachariah  Luke 1

Disclosure:
I have no personal relationship with any commercial interest.

significance of photos…

Anne of Green Gables Disclaimer:
“…and although I say far too much,
yet if you only knew
how many things I want to say and don’t,
you’d give me some credit for it.”

Anne to Marilla
in
Anne of Green Gables
By L. M. Montgomery

“Smorgasbord” Disclaimer:
Lots of text:
for reference later & language help
Resources annotated and another list at end
Note what is most compelling for you
Think about your own stories & experiences
I don’t mind dying...I just don’t want to be there when it happens.

Woody Allen

Thank you for inviting me

my views are based on 26+ years of caring for seriously ill patients and their loved ones

Know their vulnerability and that complete autonomy is a myth—We’re all connected...and that’s a good thing!

Acknowledge diverse opinions & backgrounds

Vast majority who favour these options do so on grounds of compassion

Complex issue--not simplistic—need nuanced, civil discourse

Many good reasons to oppose these practices:
Evidence from scientific studies
Experience in other jurisdictions
Some faith-based considerations

Everyone makes decisions based on a set of philosophical principles.

Respectful, civil discourse is hard to find

While religious and philosophical ideas should be perfectly acceptable as part of public discussions in a democracy, this is seldom the case at present.

Need to attempt to “speak the language” of our fellow-citizens and colleagues
Euthanasia and Assisted Suicide:
Definitions:

Assisted Suicide: “prescribing the pills”
(providing the means for person to take his own life)

Euthanasia: “pushing the syringe”
(directly & intentionally ending the person’s life)

Significance of “intent” in our legal system

E/PAS are NOT:
1) Withholding or withdrawing medical treatment that is useless (futile) burdensome or extra-ordinary.
2) The proper use of large doses of pain killing drugs to relieve suffering.
3) The proper use of sedation with a regimen of drugs to relieve the suffering of a person.
4) “Aid in Dying,” or “Assisted Death”—palliative care can be aid in dying. “Aid in Dying” and “Assisted Death” are euphemisms created by the euthanasia lobby.

Carter et al. Decision at Supreme Court of Canada (SCC)

No requirement for “terminal” dx

“irremediable condition” (includes disability)
“Intolerable suffering” (specifically includes psychological suffering)
Not amenable to treatment acceptable to that individual

Who do you say “no” to & on what basis?

Carter et al. Decision at Supreme Court of Canada (SCC)

Used right to life, liberty and security of person as rationale

NB: individual “competent” at time of PAS/E Would exclude dementia patients—for now

Gave Parliament one year to attempt legislation (Also note: Parliament did act multiple times) Still illegal now
SCC said nothing in the ruling would compel physicians to participate, but left it to the regulating bodies to “balance” the rights of patients and physicians.

Not encouraging with events in Ontario and Saskatchewan colleges (provincial licensing bodies for physicians)

May be compelled to refer or even do it

Either referral is integral part of the process & therefore referring makes one complicit
OR patients can self-refer & therefore do not need a referral

Canadians do not “refer” for capital punishment

Also rejected capital punishment because of concern for even one “wrongful death”

Justice Lynn Smith in original decision:

Admitted some collateral damage:
Like any other “medical procedure”

Said there is no difference between killing and allowing to die

Felt Canada could do better than other jurisdictions

Justice Lynn Smith in original decision:

Her analysis of witnesses & evidence e.g. *Hendin vs Battin*

SCC used her analysis

Irish High Court concerned by other jurisdictions and reached opposite conclusions
Carter et al. Decision (SCC)

Big change in Canadian Law

First time all lives are not protected
First time the court says some lives are not worth living, that death would be better than living that life, and that the government will help those people to die either by providing means for them to kill themselves, or by directly killing the person through state-sanctioned programs.

E/PAS: Some form legal in:

AS: Oregon, Washington and Vermont in US; ("limbo" in Montana & New Mexico)

E: The Netherlands; Belgium; Luxembourg; Switzerland

Quebec: Euthanasia bill—awaiting law

Germany: policy of non-prosecution

In addition: multiple governmental hearings world-wide plus ballot initiatives & legislative debates

E/PAS in the news everywhere:

Massive media attention
—much of it very friendly to the “pro” ideas

“Don’t ask so you don’t have to tell!”
Seldom ask the hard or probing questions
—especially about what is happening where these practices are legal.

E/PAS public discussions focus on:

Autonomy
Individual “rights”
Avoiding suffering
Disability as “indignity”
Two important themes in civic arena:

Public safety
Preserving our social heritage of caring

Public safety problems are more obvious
But…need to understand ethos of society

Public safety
Vulnerable people at risk
Protected by being risk averse
Problems & expansion where already legal
Hubris of simplistic thinking

Societal Ethos

Need to reclaim terms..
Language has been high-jacked:
(Thanks to Dr. Tom Koch for these insights)

Supporters of E/PAS say:
“end of life decision making”
but mean “deciding to end life”

It is not about “aid in dying”
but about termination (the term the Dutch use)

Societal Ethos

This is not about “autonomy” or “independence”
in a battle against “medical paternalism.” People
are free to autonomously refuse care. People are
free to commit suicide, a choice we may lament
but cannot always prevent. Rather it is about the
desire of some for us to accept their judgment
that life is not worth living, embrace and facilitate
their deaths through medical interventions
approved by the state and supported by it.
Societal Ethos

It is not about “dignity,” but rather hubris. Disability lawyer-activists like Harriet McBryde-Johnson and Diane Coleman repeatedly point this out. Equating the need for help with indignity assumes only the purely independent are worthy of continuance.

So it is not “whose life is this?” but “what life will we support, as a people, and what deaths will we encourage through our programs?”

See also Bill Peace’s blog post Dec 24, 2013:

My recent experience in Boston testifying in opposition to H1998 helped me understand where proponents of such legislation have gone wrong: they have turned the debate surrounding the end of life into a public policy question. At no point are the larger cultural implications of assisted suicide legislation considered. This reduces the debate to be about individuals rather than about the social forces that drive one to conclude their life has no value and death is preferable to life. To me, this is a socio-cultural tragedy not an individual failure or issue of choice. More to the point, lives are at stake. This was on full display symbolically in Boston. Proponents of assisted suicide wore blue stickers that read “My life. My Choice. My death.” This slogan is wrong. Simply put, no human being dies in a social vacuum. Death is never about an individual alone.

http://badcrippl.blogspot.ca/2013_12_22_archive.html
(the entire post is excellent)

Dr. John Wyatt

What the “compassion” of these practices is really saying:

“I care about you so much that I am willing to kill you or to provide the means for you to kill yourself”

No such thing as a death that only affects the person who died.

Also, already limit autonomy in many ways:

- No smoking
- Speed limits
- Prohibit drinking and driving
- Quarantines for Ebola and other diseases
- Prohibit use of pesticides on private property
- Limit animals in the city

Goal: community protection
What kind of social world do we want to leave for our grandchildren?
Are we being good stewards of our cultural heritage of respect for life?

Why now?
“Why we're debating euthanasia now?”
Margaret Somerville

“Not one of the bottom-line conditions usually linked with calls for legalizing euthanasia -- that a person is terminally ill, wants to die and we can kill them -- is new. These factors have been part of the human condition for as long as humans have existed. And our capacity to relieve pain and suffering has improved remarkably. So, is some other cause the main one?...

“...I suggest it's profound changes in our post-modern, secular, western, democratic societies, and their interactive and cumulative effects. To make wise decisions about whether or not to legalize euthanasia, we need to identify and understand these changes.”
Public safety

Prudent to be risk averse
Vulnerable people at risk
Problems & expansion where already legal
Hubris of simplistic thinking

NB: Lots of information in this section since this information can be hard to find through the media

Being Risk Averse is Prudent!

--results not known for decades or centuries
10-20 years is a short time!
--cannot know all outcomes or ramifications
(e.g. introduction of the starling in Central Park or the mongoose in Hawaii)

NB opposition to nuclear power, pipelines & fracking
--potential harm is enough for opposition

February 2015

The Canadian Society of Palliative Care Physicians (CSPCP) promotes access to high quality palliative care for all Canadians. We aim to improve the quality of life of patients and families living with life-limiting conditions from time of diagnosis until death. The Canadian Society of Palliative Care Physicians supports all physicians in providing quality end-of-life care/palliative care through education and advocacy. A survey of our members in January 2015 (74% response rate) indicated that the majority of our members are opposed to legalization of euthanasia (73%) or assisted suicide (69%). The majority of our members (74%) believe that euthanasia and physician assisted suicide, if legalized, should not be provided by palliative care services or palliative care physicians. Comments from all respondents demonstrated thoughtful and diverse opinions on this very complex subject. Regardless of our respective positions, CSPCP members are united in the belief that affordable, quality palliative care should be available to all Canadians who face life limiting conditions and their families.

Possible difficulties for palliative care services:

Concern about “Dr. Death” may return
Refusal of patients to see PC team
Fear of some physicians to refer
--All leading to more patients in pain

Erosion of trust in patient relationship with health care professionals
--may not voice feelings such as “I wish I were dead” due to fear that they might be taken at face value—patients and families more alone
Possible difficulties:

Patients feel need to justify continuing to live -- especially re concerns over “being a burden”

Already see subtle pressures re finances and lack of other supports

Less than optimal conditions in many nursing homes and care facilities

Scarce resources in healthcare budgets

Parliamentary Committee on Palliative and Compassionate Care

Multi-party committee co-chaired by members from the NDP, Liberal and Conservative parties

Not to be Forgotten Care of Vulnerable Canadians


This report, released in November 2011, confirms that only about 30% of Canadians have access to proper palliative care.

Email from a Dutch medical student in July 2014:

I study in Belgium and I had a lot of classes about Euthanasia in the past year. My professors were very proud of the new euthanasia laws and have worked hard to make that possible. They were talking a lot about how good it was that they now could help the people to die a more humane death and not leave them suffering. And the message they had for [those who did not want to participate] was basically that they were inhumane to allow so much suffering, not colleague friendly because you let them do the dirty jobs and while being there for the patient throughout his/her life you just leave them in their pain of death.

You probably won’t be surprised to hear that the other students in my group thought it was ok to give Euthanasia to someone who was only 70 and thought his life was not of much use, so basically depressed without further illness.

Vulnerable people are at risk:

excellent work done by disability rights activists:

Diane Coleman
Carol Gill
Marilyn Golden
Amy Hasbrouck
John Kelly
Harriet McBryde Johnson
Bill Peace
Killing us softly: the dangers of legalizing assisted suicide; Disability and Health Journal; vol (3) Issue 1, pages 16-30, January 2010

This fear of disability typically underlies assisted suicide. "Janet Good, an assisted suicide advocate who worked with Jack Kevorkian, was clear about this: 'Pain is not the main reason we want to die. It's the indignity. It's the inability to get out of bed or get onto the toilet... [People]... say, 'I can't stand my mother—my husband—wiping my butt' [6]. But as many thousands of people with disabilities who rely on personal assistance have learned, needing help is not undignified, and death is not better than reliance on assistance. Have we gotten to the point that we will abet suicides because people need help using the toilet [7]?"

Why do patients choose assisted death?

In Oregon patients:

"cited concerns 'including the loss of autonomy (89.9%), the loss of the ability to engage in activities that make life enjoyable (87.4%), the loss of dignity (83.8%), and the loss of control of bodily functions (58.7%)’”


"Moreover, there is danger that many people would choose assisted suicide due to external pressure. Elderly individuals who do not want to be a financial or caretaking burden on their families might take this escape. In fact, the percentage of reported Oregon cases attributed to patients’ reluctance to burden their families has risen shockingly. It totaled 12% in 1998, but increased to 26% in 1999, then 42% in 2005, and 45% in 2007 [23], [24], [25], [26]. Nothing in the Oregon law will protect patients when family pressures, whether financial or emotional, distort patient choice.”
Dr. Golden’s conclusion: “In light of expansion and other dangers, leading disability rights organizations and advocates in the United States and in many countries, as well as health care providers and many others, will continue to oppose the legalization of assisted suicide and euthanasia. Instead of legalization, we will call for adequate home and community-based long-term care, universal health coverage, and a range of social supports that provide true self-determination for everyone. As Paul Longmore wrote, ‘Given the absence of any real choice, death by assisted suicide becomes not an act of personal autonomy, but an act of desperation. It is fictional freedom; it is phony autonomy.’”

Oregon: Minimal data and fatally flawed oversight:

1) noncompliance is not monitored
OPHD announced in its first year that the state cannot determine if assisted suicide is practiced outside the law’s framework, stating “[W]e cannot detect or collect data on issues of noncompliance with any accuracy.”

2) no investigation of abuse—“good faith” only standard
The Oregon Department of Human Services (DHS, of which OPHD is a part) acknowledged in a press release that DHS “has no authority to investigate individual Death with Dignity cases…”

3) death certificate
requirement that on the death certificate, a patient’s underlying disease must be listed as the cause of death—even if he or she died from lethal drugs at a time when that disease manifested no symptoms

4) underlying data destroyed annually

5) no requirement for psychological assessment

Margaret Dore, an elder law specialist, has concerns re the Oregon & Washington assisted suicide laws:

1) An heir who will benefit from the patient’s death can help the patient sign up for the lethal dose.

2) Once the lethal dose is issued by the pharmacy, there is no oversight. The death is not required to be witnessed by disinterested persons.

3) “self-administer” can legally mean someone else putting the lethal dose in the patient’s mouth or feeding tube

4) By signing the form, the client is officially saying that if he dies suddenly, no questions should be asked.

www.choiceillusion.org

Diane Coleman
an attorney in the US and one of the founders & leaders of the “Not Dead Yet” disability rights group. She often hears people say that they would rather be dead than to “endure the indignity of incontinence.”

Her response:
“It is extremely offensive to me that others would say that they would rather die than to live a life like mine…simply because I leak.”
E/PAS proponents have a double standard for suicide…

See Amy Hasbrouck’s great article:
“How About the Right to Cry for Help?”

Cartoon from “Second Thoughts”

Two excellent articles by Carol J Gill:

“Disability, Constructed Vulnerability, and Socially Conscious Palliative Care”
Journal of Palliative Care 22:3/2006; 183-189

“No, we don’t think our doctors are out to get us: Responding to the straw man distortions of disability rights arguments against assisted suicide”
Disability and Health Journal 3 (2010) 31-38

Ross Harding
1986-1996

Menkes Disease
Impaired copper transport
Serious systemic connective tissue problems
Needed Copper Histidine injections every day
Over 30 operations and countless hospitalizations
Zany, witty and wonderful
Also very insightful…

Ross Harding:

“You know Mum, if I get sick again, you don’t have to kill me. I can take it.”

“None of us gets made quite right until we get to heaven—I just got made wrong differently than most people.”
Problems and expansion where already legal:

Drs. Herbert Hendin & Kathleen Foley,
Physician-Assisted Suicide in Oregon:

A very detailed study of cases in Oregon that is fully annotated and documents many cases where the law with its supposed safeguards has not been upheld. The paper is case-based and very interesting to read.

“The evidence strongly suggests that these safeguards are circumvented in ways that are harmful to patients.” This despite the fact that the “OPHD [Oregon Public Health Division] has been issuing annual reports declaring that terminally ill Oregon patients are receiving adequate care.” (p. 1614)

The final conclusion of the article was

“As we have previously noted, under the current monitoring system, Oregon physicians appear to have been given great power without being in a position to exercise it responsibly. They are expected to inform patients that alternatives are possible without being required to be knowledgeable about such alternatives or to consult with someone who is. They are expected to evaluate patient decision-making capacity and judgment without a requirement for psychiatric expertise or consultation…"
“...They are expected to make decisions about voluntariness without having to see those close to the patient who may exert a variety of pressures, from subtle to coercive. They are expected to do all of this without necessarily knowing the patient for more than fifteen days. Since physicians cannot be held responsible for wrongful deaths if they have acted in good faith, substandard medical practice is permitted, physicians are protected from the consequences, and patients are left unprotected while believing they have acquired a new right.”

[emphasis mine]


Dr. Linda Ganzini, the principal author of this study, is a psychiatrist in Oregon.

Some of the conclusions of the article include:

“Physicians in Oregon who received requests for aid in dying from 143 patients after enactment of the Death with Dignity Act reported that 20% were depressed—a proportion comparable to what we found in this study.”

Data from Oregon show that the most consistent reason that patients in Oregon chose to take the lethal medication was because of a fierce independence.

In fact, in one study by Dr. Linda Ganzini, the families of patients who had taken the lethal dose were asked to rate the severity of all symptoms during the time before the decision was made to do so. No symptom (including pain) was rated at a level of greater than 2 out of a possible 5.

Ganzini et al., J Gen Intern Med. 2008 Feb; 23(2):154-157

“In contrast, studies of interest in euthanasia from populations outside of Oregon suggest that depression and psychosocial distress are prominent among patients who endorse an interest in hastened death. For example, in a study of 200 terminally ill inpatients with cancer, the prevalence of depressive syndromes was 59% among patients with a serious and pervasive desire to die but only 8% among patients without such a desire.

In 2014 – 105 people died by assisted suicide in Oregon, only three of them had a psychological assessment.

Oregon’s statistics for the last five years show that only 2 percent of patients are being referred for psychological evaluations.

Depression is a treatable illness

A study was published in the Canadian Medical Association Journal in June 2010, and showed that in Belgium where PAS and Euthanasia are legal with supposed strict safeguards, 66 of the 208 patients (32%) who died by physician assisted death had not made an explicit request for assisted death and many would not have been competent to make such a request.


...tended to be those: with non-cancer diagnoses, such as dementia, older and less mentally competent.

About 9% of the time, the physician said the reason consent was not sought was that “It would be too stressful for the patient.”

NB the doctors themselves believed they had euthanized the patient. Therefore, even if the procedure they carried out did not strictly fit the definition of euthanasia, that is not relevant because they were willing to do it while believing they had carried out euthanasia.

Belgian update: NEJM March 17, 2015:

4.6% all deaths—euthanasia, PAS 0.05%
1.7%—no explicit consent—1,000 deaths yearly

2014 Stats Canada: 242,074 deaths

4.6% = 11,184 (tied with 4th leading cause of death—lung disease)

Only cancer, heart disease and stroke greater numbers)

1.7% = 4,115 (between 8th and 9th leading causes of death)
Alex Schadenberg’s analysis of the Belgian studies:

Only about half of deliberately hastened deaths are even reported

Those reported—followed guidelines
Unreported were usually never intended to be reported and did not follow guidelines—more vulnerable groups

“Exposing Vulnerable People to Euthanasia and Assisted Suicide”
Alex Schadenberg—2012

(Executive Director of the Euthanasia Prevention Coalition)

In November 2013, Alex Schadenberg debated Dr. Jan Bernheim, one of the pioneers of the Belgian euthanasia law. During the debate in Brussels, Alex quoted from the Belgian studies showing that euthanasia deaths were occurring without request, that euthanasia deaths were not being reported and that nurses were ignoring the law and euthanizing their patients.

Bernheim responded to those statements by saying: “There are problems with the Belgian euthanasia law.”

Even a Belgian proponent of the law admits problems

As the prohibition against killing patients has eased, the practice has expanded. In the Netherlands and Belgium, there are protocols for the euthanasia of newborns whose lives are deemed to be burdensome to the child and/or his family.

In the Netherlands this is called the Groningen Protocol.


In a study published in Acta Paediatrica in 2007, it was reported that in deaths of all children under one year of age drugs were administered with the explicit intention of hastening death in 9 per cent of cases in Belgium and 7 per cent of cases in the Netherlands.

In Belgium only 81 per cent of physicians discussed any aspect of End of Life Decision (ELD) making with the parents. In the Netherlands the number was 96 per cent.
This means that in Belgium, 19 per cent of the time, the parents were never consulted, much less asked for their consent, about any aspect of ELD, the physicians made the determinations with no input whatsoever from the families.

1 in 5 of these children were killed without the parents ever being asked if they would like to take the baby home and love him or her.

Vrakking AM et al., Department of Public Health, Erasmus MC, University Medical Center Rotterdam, The Netherlands.

Euthanasia and minors:
“Minors may themselves request euthanasia from the age of 12, although the consent of the parents or guardian is mandatory until they reach the age of 16. Sixteen and seventeen-year-olds do not need parental consent in principle, but their parents must be involved in the decision-making process. From the age of 18, young people have the right to request euthanasia without parental involvement.”


Other Examples:
- Deaf Belgian twins facing potential blindness
- Young person with botched sex change operations
- Anorexia patient
- Depressed mother
- Person in prison for life
- Patient with severe tinnitus
- Dutch wife’s ultimatum to husband: Euthanasia or nursing home
- Doctor knew coercion and ended man’s life

Healthy elderly couple in Belgium died by euthanasia.

Their own doctor refused to grant their son, John Paul, his request for euthanasia for his parents, so he shopped around until he found an unnamed hospital in Belgium that did it.

John Paul’s comments:
It was “the best solution”. “If one of them should die, the one who would remain would be so sad and totally dependent on us.”
“Deaf Belgian twins going blind choose to be euthanized”


“We think the federal government has no place at the bedside of seriously and incurable ill Canadians who have made firm decisions about the amount of care they wish to receive at the end of life,” said Grace Pastine, who represents several individuals and the B.C. Civil Liberties Association.

Patients already have the right to refuse or withdraw any treatment, no matter how life-saving. Is the BCCLA advocating a complete absence of regulation of the medical profession in when caring for seriously ill patients?

Pastine said her clients were deeply disappointed by the Court of Appeals ruling (later reversed by SCC).

“What this means is that, at least for the moment, seriously and incurably ill individuals will continue to suffer against their wishes at the end of life without the choice and the dignity that they deserve.”

Who decides what is dignified?
If you have a serious or incurable condition, are you without dignity unless you commit suicide or are killed by a doctor?

Inevitable expansion already seen as a “good”

“[T]here are many individuals whose lives are no longer worth living to them who have not been diagnosed with a terminal illness. They may be suffering greatly and permanently, but are not imminently dying. There is no principled basis for excluding them from assisted suicide.”


Downie was a member of this Panel.
All cited in CMAJ letter by Dr. Will Johnston
A piece Dr. Cottle wrote in response to the confiscation of “suicide kits” sold in Oregon by an elderly lady from California...

Despite the alarm in the Oregon legislature, it should come as no surprise that the unfortunate young man from Eugene saw suicide as an attractive option. His decision is a logical application of the ethos of the Death with Dignity Act in Oregon that came into effect in 1995. Although assisted suicide is supposedly available only to those with terminal diagnoses, hastened death in Oregon is now legal and erroneously considered “compassionate” and “rational.” In September 2011, an Oregon Public Health report provided evidence of the spread of the suicide contagion. The report expressed great concern that the suicide rate from all causes in Oregon is now 15% higher than the national average. The report noted, “After decreasing in the 1990s, suicide rates have been increasing significantly since 2000.” It goes on to state, “The single most identifiable risk factor associated with suicide is depression. Many people can manage their depression; however, stress and crisis can exacerbate their ability to cope successfully.” The available official response to this tragic situation has been to strengthen programs and to increase resources to address suicide risk factors, but there are no safeguards in place for those seeking hastened death who are facing terminal or life-limiting diseases. Official reports from Oregon in recent years confirm that patients have never received any psychological, psychiatric, or neurocognitive assessment before the lethal drugs were dispensed. This is especially disturbing in light of a study of 300 terminally ill cancer patients who identified depression as a predominant 55% of those requesting hastened death, while only 8% those who were not requesting hastened death showed signs of depressive symptoms. Chochinov HM, Willson KB, Enns M, et al. Desire for death in the terminally ill. Am J Psychiatry 1999; 156:1130-9.

Of course the suicide kits should be confiscated to protect people whose depression or despair might tempt them to take their own lives. The real question is why a double standard tolerated? True compassionates community support and excellent medical care should be the standard for every person who contemplates a hastened death for any reason. Oregon’s Death with Dignity law has allowed the suicide contagion to increase and people who are vulnerable due to illness or disability are put at risk instead of receiving the care they need and deserve.

The notion that patients are making use of this law because of uncontrolled pain and other symptoms is simply not supported by the data.

Dr. Donald Low

News reports said that he died at home in his wife’s arms and did not have pain.

Yet, somehow he still considered his death to be undignified.

Medical Hubris to assume we can predict accurately and determine the depth of another’s suffering or the value of another’s life.

Jeanette Hall
Patient of Dr. Kenneth Stevens
Diagnosed with cancer in 2000
Delighted to be alive today because Dr. Stevens “stalled” her decision

http://alexschadenberg.blogspot.ca/2013/12/janette-hall-i-say-no-to-assisted.html

Dr. Balfour Mount
Founder of Palliative Care in Canada--

“Whatever my situation is now or may become, I cannot imagine arguing that the vulnerability of countless others is trumped by my challenging circumstances.”

Dr. Mount is living with his third cancer now.
Note discrepancies already present:

Geriatric wards vs pediatric ones
Pediatric rehab facilities vs nursing homes

Dogs: demand for “no kill shelters” vs euthanasia

Jon Katz--author of The New Work of Dogs
USA Today Book Club:

Delaware: Jon, the book includes a really stunning chapter about a woman who is deeply involved in a dog rescue group. She and her comrades are always riding into a pound in Brooklyn and bringing out as many dogs as they can to be adopted into loving homes. You sounded both admiring and a little alarmed about this woman and her group -- am I right? What do you think of this rescue phenomenon?

Jon Katz
USA Today Book Club:

Jon Katz: Thanks for the perceptive question. I found Betty Jean heroic and troubling. She places more than 500 dogs a year in private homes, but at enormous expense to her personal life. She rarely sees her children or grandchildren and hasn’t seen a movie in five years. …

Jon Katz
USA Today Book Club:

…There is a vast subculture of “transporters” and “screeners” “fosters” and people who follow up to make sure the dogs are doing well. While I’m in awe of their heroic work, I’m also conscious of the fact that there is no equivalent national network for troubled humans. If you type “dog rescue” into Google, you get nearly 3/4 of a million hits.

If you type “people rescue” you’ll get five or six.
Parker Palmer

“Violence is what happens when we don’t know what else to do with our suffering.”

“I think that axiom applies on every level of life. When individuals don’t know what to do with their suffering, they do violence to themselves or others near them.”

Montreal palliative care meeting

Dr. Serge Daneault, PC in Quebec

?Why now for E/PAS?
--difficulty with accompanying suffering patients and families ourselves?
--not teaching our learners the skills?

compassion literally means to “suffer with” “accompany” in French—to be radically present

Think about our language..

Try to eliminate the word “burden” from all our discussions

Try to use “health care professionals” instead of “health care providers” —care is not a commodity to be purchased by a consumer

What are the implications for people living with disabilities if society’s goals change from mutual support and compassion to providing death as a “solution” to those experiencing any type of suffering?

Who decides what suffering “qualifies” for euthanasia?

Who do you say “no” to and on what grounds?
Circa 400 BC, Hippocrates and his followers began a movement that changed the face of medicine and the culture in general.

“Medical killing” was the norm at the time of Hippocrates.

Patients feared the “healers”

This Hippocratic heritage of respect for life is like an old growth forest—easy to destroy and impossible to replace.

We are responsible for our *metaphysical* environment just as much as for our *physical* environment.

What legacy will we leave for our grandchildren?

“Do no harm”

I will follow that method of treatment which according to my ability and judgment I consider for the benefit of my patient and abstain from whatever is harmful or mischievous. I will neither prescribe nor administer a lethal dose of medicine to any patient, *even if asked*, nor counsel any such thing nor perform act or omission with direct intent deliberately to end a human life.

Excerpt from Hippocratic Oath: Registry of Hippocratic Physicians

[www.hippocraticregistry.com](http://www.hippocraticregistry.com)

Students were required to affirm the oath before beginning their studies.

Professor Theo Boer, Dutch Ethicist:

I used to be a supporter of legislation. But now, with twelve years of experience, I take a different view. At the very least, wait for an honest and intellectually satisfying analysis of the reasons behind the explosive increase in the numbers. Is it because the law should have had better safeguards? Or is it because the mere existence of such a law is an invitation to see assisted suicide and euthanasia as a normality instead of a last resort? Before those questions are answered, don’t go there. Once the genie is out of the bottle, it is not likely to ever go back in again.

See Alex Schadenberg’s blog for complete text

*July 16, 2014*
But, how do we help?

Dr. Harvey Max Chochinov has a substantial body of fascinating, peer-reviewed published work which has elucidated some of the factors involved in the concept of dignity and how dignity can be preserved and strengthened in clinical settings. His article in the British Medical Journal about the A,B,C,D’s of dignity is an excellent place to begin.


Interesting studies about coping and resilience for patients, caregivers and health care professionals.

How do we support and enhance coping and resilience and what factors determine the best outcomes?

“Meaning-centered Therapy”

Dying Well

Dr. Ira Byock

“Imagine your patients well.”

healed vs cured

The founder of modern Palliative Care:
Dame Cicely Saunders, MD

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Dr. Balfour Mount
Founder of Palliative Care in Canada--

"Our patients need to experience that we are with them as fellow-travellers on this voyage; we must keep in mind that, at best, we are wounded healers."

Don Quixote:

“For it is still some comfort in misfortune to find one who can feel for it.”

(Part I Ch 24)

Louisa May Alcott
Author of *Little Women*
“The next night, as I went my rounds with Dr. P., I happened to ask which man in the room probably suffered most; and, to my great surprise he glanced at John...’He won’t last more than a day or two, at furthest...you’d better tell him so before long: [women have a way of doing such things comfortably, so I leave it to you....]’ It was an easy thing for Dr. P. to say: ‘Tell him he must die,’ but a cruelly hard thing to do....

A few minutes later...I saw John sitting erect, with no one to support him, while the surgeon dressed his back...[he] looked lonely and forsaken just then, as he sat with bent head, hands folded on his knee, and no outward sign of suffering, till, looking nearer, I saw great tears roll down and drop upon the floor....My heart opened wide and took him in, as, gathering the bent head in my arms, as freely as if he had been a little child, I said, ‘Let me help you bear it, John.’

Never, on any human countenance, have I seen so swift and beautiful a look of gratitude, surprise and comfort, as that which answered me more eloquently than the whispered--‘Thank you, ma’am, this is right good: this is what I wanted!’ ‘Then why did you not ask for it before?’ ‘I didn’t want to be a trouble; you seemed so busy, and I could manage to get along alone.’ ‘You shall not want it any more, John.’

Louisa May Alcott
Written from the Union Hotel Hospital;
US Civil War nursing experience

Theme of a care-giving conference:
“90% of caring is just showing up.”

Some are more “natural” carers
Everyone can learn
Find your comfort zone; use your gifts
Need “margin” to care
Teague, an 11 year old boy from BC who had cerebral palsy, wrote this response to the Latimer case in 1995.

I have a friend who had cerebral palsy, and he decided that life was too hard and too painful. So he really let himself die. I knew he was leaving this world and letting himself dwell in the spiritual world. I told him that I understood that the spiritual world was really compelling, but that life was worth fighting for.

"My name is Teague. I am eleven years old, and have really severe cerebral palsy. The Latimer case in Saskatchewan has caused me a great deal of unhappiness and worry over the past few weeks."

I feel very strong that all children are valuable, and deserve to live full and complete lives. No one should make the decision for another person on whether their life is worth living or not.

I had to fight to live when I was very sick. The doctors said I wouldn’t live long, but I knew I had so much to accomplish still.

I have to fight pain all the time. When I was little, life was pain. I couldn’t remember no pain. My foster mom, Cara, helped me learn to manage and control my pain. Now my life is so full of joy. There isn’t time enough in the day for me to learn and experience all I wish to. I have a family and many friends who love me. I have a world of knowledge to discover. I have so much to give.
I can't walk or talk or feed myself. But I am not "suffering from cerebral palsy." I use a wheelchair, but I am not "confined to a wheelchair." I have pain, but I do not need to be "put out of my misery."

My body is not my enemy. It is that which allows me to enjoy Mozart, experience Shakespeare, savour a bouillabaisse feast, and cuddle my mom. Life is a precious gift. It belongs to the person to whom it was given. Not to her parents, nor to the state. Tracy's life was hers "to make of it what she could."

My life is going to be astounding.

Teague Johnson
North Vancouver
Teague died five months later on May 29, 1995.

Practical Things to Do (or ask for) in Difficult Times

1. listen and pray
   music or story CDs or mp3s
   read books or the Bible aloud or record them
   choose a movie or show to watch together
   buy and/or wrap Christmas or birthday gifts
   visit patient to relieve care-giver
   mobile "spa" (beware fragrance sensitivities)
   provide meals & return empty dishes to owners
   be "telephone/email headquarters"
   Caringbridge; meal website
   set up a sign-up sheet or book—call/email others
   (especially re house & yard work, errands, etc.
   N.B. time limited and specific)
   "adopt" a child or help with children
   apologize if you "goof"
   laugh & remember together--write down memories

Ways that out of town family members can assist

Financial (eg. Pay for caregiver or cleaner)
Provide respite
Write story of patient's life (include photos)
compile music the patient loves
Read stories or the Bible in your own voice
CALL often—both patient and caregiver
Listen empathetically
Be supportive not critical
Send gifts and cards or letters

Stinging Nettle
One interesting feature is that if one grasps the nettle very firmly, the trichomes are crushed, and are not able to inject the irritating chemicals.

It is only when one brushes lightly against the plant that the painful sting occurs.

This is a fitting example of the difference between just brushing up against suffering or dying versus grasping with both hands the opportunity to accompany one another in difficult times.

One results only in pain, the other, in many benefits.

And now I will show you the most excellent way...

If I speak in the tongues of men and of angels, but have not love, I am only a resounding gong or a clanging cymbal. If I have the gift of prophecy and can fathom all mysteries and all knowledge, and if I have a faith that can move mountains, but have not love, I am nothing. If I give all I possess to the poor and surrender my body to the flames, but have not love, I gain nothing.
Love is patient, love is kind. It does not envy, it does not boast, it is not proud. It is not rude, it is not self-seeking, it is not easily angered, it keeps no record of wrongs. Love does not delight in evil but rejoices with the truth. It always protects, always trusts, always hopes, always perseveres. Love never fails.

1 Corinthians 12:31-13:8

“The most important message is the unspoken one to the world at large: that this ‘dead loss to society,’ this dying woman or handicapped man, is infinitely precious. If I as a doctor spend an hour of my clinic time talking to a woman who has only a few weeks to live, I am making a clear statement of her worth.

I am giving her time that could have been spent with people who will get better, who will be able to contribute once again to the common good. I am affirming the worth of one individual person in a world in which the individual is at risk of being submerged or valued for his strength, intellect or beauty.
It is a prophetic statement about the unique value of the human person irrespective of age, social class, or productivity. It is an affirmation that people matter just because they are people, because God made them and loves them, just the way they are, not because they are good or witty or physically beautiful."

Sheila Cassidy, MD

In a Christian context:

My friend's comment:  
"I don't know what to think."

"Do not kill" is fairly basic

Do we trust in God and His plan for our lives?

God is in control

Job 12:10 In his hand is the life of every living thing and the breath of all mankind.

Psalm 31:15a My times are in your hands

Psalm 139:16 Your eyes saw my unformed body; all the days ordained for me were written in your book before one of them came to be.

We are not our own

1 Corinthians 3:16-17 Do you not know that you are God's temple and that God's Spirit dwells in you? If anyone destroys God's temple, God will destroy him. For God's temple is holy, and you are that temple.

1 Corinthians 6:19-20 Or do you not know that your body is a temple of the Holy Spirit within you, whom you have from God? You are not your own, for you were bought with a price. So glorify God in your body.
Created in God’s Image

*Imago Dei*

So God created mankind in his own image, in the image of God he created them; male and female he created them.

*Genesis 1:27*

Commanded not to deface his image

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No such thing as a death that only affects the person who died.

No one lives completely independently

Independence is not a Christian virtue -- interdependence is

“Bear one another’s burdens, and so fulfill the law of Christ.” *Gal 6:2*

The Person of God is a “community”

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Creativity and imagination can help us to concentrate on care, not killing.

Caring for each other is a fundamental part of our Canadian identity as well as our Christian birthright.

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Concepts of:

*Home*

*Emmanuel*

People are hungry for home and for God to be with them and as Christians we have so much to share about both with our neighbours!

We have Hope!
A tale of two necklaces…

Pearl necklace from Haarlem, NL, near Corrie ten Boom’s home—caring for vulnerable people provides a “Hiding Place” in our own days.

Coin necklace: “lepta” from Jesus’ time—the “widow’s mite” from Mark 12:41-44. Jesus sees and blesses our faithfulness—even when it is only “ordinary” to everyone else. He knows what it costs us and remembers.

Our charge from the Lord to care for the vulnerable

For pastors & leaders:
Think about how to plow the hard ground in people’s hearts and minds that has been beaten down by our culture… then plant and water the seeds of life.

Capture the imagination of our neighbours and our culture about the kind of world we want to have.

What can you do as a Christian?

Pray!
“**The prayer of a righteous person has great power as it is working.**” James 5:16

Be people of hope:
“**May the God of hope fill you with all joy and peace in believing, so that by the power of the Holy Spirit you may abound in hope.**” Romans 15:13

Suggestions for action:

Get informed

Go to your own community
--tell your stories
--share what is most compelling to you
--speak to the best in others
Suggestions for action:

become familiar with 1 or 2 papers or news stories
Remember: you are a “witness for the defense” and need only introduce doubt
learn your “elevator speech” by heart --stay on topic

Suggestions for action:

Donate funds to important causes
Contact government representatives and officials
see: www.GiveUsTime.ca
Consider joining the Euthanasia Prevention Coalition

Resources re Euthanasia and Physician Assisted Suicide:

Alex Schadenberg, Executive Director of the Euthanasia Prevention Coalition:
blog: http://alexschadenberg.blogspot.ca
EPC news and information site: www.euthanasianewsworld.com

Alex’s helpful short book:
“Exposing Vulnerable People to Euthanasia and Assisted Suicide”
Alex Schadenberg--2012

Resources re Euthanasia and Physician Assisted Suicide:

The Christian Medical and Dental Society of Canada
Many resources, including a video (The Gift), a powerpoint presentation available for anyone to use, and other tools at the CMDS Canada website:
www.cmdscanada.org
Resources re Euthanasia and Physician Assisted Suicide:

FOCUS magazine at CMDS Canada website:

FOCUS issue about the Christian perspective on E/PAS:

FOCUS issue about how to discuss E/PAS in secular settings:
(includes annotated bibliography of articles in the scientific literature)
http://www.cmdscanada.org/my_folders/FOCUS/FOCUS_32.2_low_res.pdf

Life-Giving Love:
A National Campaign for Palliative and Home Care: Against Euthanasia and Assisted Suicide
www.lifegivinglove.com (in both English and French)
Supported by the Canadian Conference of Catholic Bishops and the Catholic Organization for Life and Family

CMDA website in the US: www.cmda.org

Center for Bioethics and Human Dignity
an extensive bibliography on their website:
https://cbhd.org/end-life/bibliography

Excellent new monograph by Ryan T Anderson, PhD

“Always Care, Never Kill: How Physician-Assisted Suicide Endangers the Weak, Corrupts Medicine, Compromises the Family, and Violates Human Dignity and Equality”
March 24, 2015

www.heritage.org

United Kingdom: www.carenotkilling.org.uk

Dr. Tom Koch’s website: www.kochworks.com

email address:
Margaret Cottle: mmcottle@mac.com
In the great sweep of human history, it is not really a “circle of caring” that we experience. We are carried along in a vast river of caring that flows from generation to generation to generation, buoying us up during the times when we need to be cared for, and refreshing us in the seasons when we are the carers. The love we give and receive is both powerful and healing. It’s time for our generations to pass along this heritage to the next ones, and to protect this river from those who would destroy or diminish it in any way.

I am including a bonus slide with a link to a short but fascinating interview with Dr. Diane Meier, a physician in NY, who was at one time in favour of physician assisted suicide and has changed her mind--for both practical and philosophical reasons.

It is definitely worth reading.

Diane Meier:
Interview with Diane Meier, MD
director of the Center to Advance Palliative Care
in New York, a professor of geriatrics and internal medicine at the Mount Sinai School of Medicine
and the school’s Catherine Gaisman Professor of Medical Ethics
in the online journal HemOnc Today