"First, do no harm" (Latin: *Primum non nocere)*

—Traditional

Ethical Issues at the Beginning and at the End of Life

Opening Words

From early version of Hippocratic Oath
(About 3 centuries BCE)
Delivered by Dr. Donn Teubner-Rhodes

Our opening words come from an early version of the Hippocratic Oath.

I swear by Apollo the Healer, by Asclepius, by Hygieia, by Panacea, and by all the gods and goddesses, making them my witnesses, that I will carry out, according to my ability and judgment, this oath and this indenture.

Into whatsoever houses I enter, I will enter to help the sick, and I will abstain from all intentional wrong-doing and harm, especially from abusing the bodies of man or woman, bond or free.

And whatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secrets.

Now if I carry out this oath, and break it not, may I gain for ever reputation among all men for my life and for my art; but if I break it and forswear myself, may the opposite befall me.

Chalice Lighting

#458
(Read in unison)

Prelude

"Gavottes" (transcribed from *Suite No. 6 in D for Cello*)
J.S. Bach
Zoë Stewart, guitar

Story

The Golden Rule
By Ilene Cooper, illustrated by Gabi Swiatkowska

[Story summary: A grandfather and his grandson see a billboard on which is written "Do unto others as you would have them do unto you." The boy asks his grandfather to read it to him, and thus begins a discussion of the Golden Rule. Grandfather explains to the boy that the rule is for everyone, adult and child alike, and has been expressed in different words by religions all over the world. The Christians say, "You should love your

neighbor as you love yourself."

The Jews say, "What is hateful to you, do not do to your fellow humans."

In Islam, the rule is stated, "Hurt no one so that no one will hurt you."

Grandfather continues restating the Golden Rule in the words used by other religious groups. Intrigued, the boy asks his grandfather how he might begin his own practice of the Golden Rule. Grandfather instructs him that it all begins in his imagination, thinking about how another person feels. How might a new child in class feel, for example?

The boy considers the feelings of a child new to the class, and posits that the child might feel scared. Coached by his grandfather, the boy thinks of things he might do to lessen the fear of the new child. And so the boy's imagination is engaged as the grandfather gently leads him to consider his own feelings, and how they might be shared by others. The boy begins to think of things he might do to keep the Golden Rule, like telling the truth because he does not like being lied to.

And when he learns that the Golden Rule has been around for thousands of years, he realizes that the world would be a better place if it were practiced more often. The story ends as Grandfather says, ". . . you can't make everyone in the world practice the Golden Rule. There's only one person you can ask to do that."

"Me?"

"You. It begins with you."]

Hymn

#123 "Spirit of Life"

MEDITATION

"No Themes Are So Human"
By Henry James

Let us continue in the spirit of prayer with a meditation that comes from the preface of the story *What Maisie Knew,* by Henry James. "No themes are so human as those that reflect for us, out of the confusion of life, the close connection of bliss and bale, of the things that help with the things that hurt, so dangling before us forever that bright hard medal, of so strange an alloy, one face of which is somebody's right and ease and the other somebody's pain and wrong."

In moments of silence let us reflect on the close connection of bliss and bale. What guides you when before you dangles the bright hard medal, one face of which is someone's right and ease, and the other someone's pain and wrong? Henry James observes that our purpose as human beings is "to live with all intensity and perplexity and felicity in this terribly mixed world . . . sowing on barren strands . . . the seed of the moral life."

Musical Interlude

"The Life I've Been Given"
Rachel Allen/Tim Coles, arr.
TUUC Choir

Homily

Ethical Issues at the Beginning of Life
Dr. John LaFerla

Today we heard a story about the Golden Rule and the various ways the same basic ethic has sprung up all around the world for as long as we can remember. The principle of "do unto others" helps guide our actions in daily life. But when it comes to the practice of medicine, the Golden Rule is simply not enough. Many more rules exist and have evolved over the centuries, starting with the Hippocratic oath, of which you heard an excerpt this morning.

That being said, how does medical ethics qualify as a topic for the pulpit this morning? The answer is that, when you get down to its very core, medical ethics is about trust, it is about telling the truth, and having compassion. These ideas are, of course, bedrock UU principles as well. Another reason to explore medical ethics is that everyone in this sanctuary has had or will have some contact with the medical care system, so it would be good to know more or less what to expect.

This morning you are hearing from several physicians who are members of this congregation, but none of us are specialists in medical ethics. When I started medical school, 50 years ago, there were no courses in the curriculum dedicated to this topic. It was one of those things you were supposed to pick up by watching the older physicians, and of course reading and debating about challenging cases. Today, large health care systems have institutional review boards to consider appropriate safeguards for research proposals, and hospitals have experts on staff to consult when needed in thorny cases. Think tanks and institutes have evolved that focus all of their attention on the ever-evolving field. A famous one is the Hastings Institute in New York, and the one closest to us is the Berman Center for Biomedical Ethics at Johns Hopkins.

We all have idea of what medical ethics is about: maybe the idea of informed consent comes to mind. Maybe you have heard the Latin phrase *Primum non nocere,* which translates as "First do no harm." Many people assume this is part of the Hippocratic Oath, but it is not. It is believed that the term was actually coined by a 19th century surgeon named Thomas Inman.

Or you may think of a bill pending right now in the Maryland legislature referred to as Death with Dignity, addressing a person's right to decide to end their own life in certain circumstances. Or you may think about someone you know who is coping with an unplanned pregnancy, trying to decide what is right to do.

Let's pause a moment to talk about the difference between ethics and morals. These terms are often used as interchangeable, but they are not the same. Morals refer to beliefs that are held to be basic and universal, like thou shalt not commit murder. A sense of "being good" and knowing right from wrong is built into our DNA.

Ethics, on the other hand, refers basically to a code of conduct. It consists of a list of principles or rules to be followed by members of a specific profession. Doctors, teachers, lawyers, preachers, and other professionals are

expected to conform to certain rules for their particular profession. So the term *medical ethics* means a guide to appropriate conduct for medical professionals. It covers not just physicians, but nurses, psychologists, midwives, dentists, physicians' assistants, podiatrists, and many others. Today, when I refer to "doctor," I mean any individual working in the healing professions.

Ethical codes are specific for particular groups in a given time and place. These codes may vary in different parts of the world, and may change over time; in contrast to basic moral principles, they are not "written in stone." For example, the Hippocratic Oath, written about 2,500 years ago, has been modified many times over the centuries to fit the modern ideas of the day. While it may seem ethical to limit childbearing to one per family in China, Americans would find that coercive and abhorrent.

Medical Ethics in general is organized into four main areas or principles:

- Autonomy
- Justice
- Beneficence
- Non-Malfeasance

Autonomy refers to the integrity of one's body and decisions made about it. This means that a doctor cannot perform surgery or other therapy without the express consent of the patient. Part of this is the need for the doctor and patient to explore and understand risks and benefits, and for the individual to have final say as to what is done to his or her body.

Justice refers to the idea that the burdens and benefits of new or experimental treatments must be distributed equally among all groups in society. Issues to be considered include fair distribution of scarce resources, competing needs, rights and obligations, and potential conflicts of interest.

Beneficence requires that a contemplated procedure be done with the intent of doing good. It also demands that health care providers continually update their skills and training to maximize the benefit for their patients and the public at large.

Non-malfeasance requires that a procedure does not harm the patient involved or society. This principle may be breached or be subordinate to a greater good in many circumstances, but it always must be kept in mind.

Now that we have this package of principles, let me describe some real-life cases in which ethical principles may conflict with one another or be difficult to sort out.

There are too many topics of interest to deal with in one morning, so we are going to focus on beginning of life and end of life. Other ethical areas, like informed consent, use of placebos, mental health concerns, confidentiality and more will be saved for another time.

Case 1: A childless couple present for help. She has had hysterectomy, so cannot carry a child. You, her physician, have found a healthy volunteer to carry their pregnancy. An ovum is obtained from your patient, fertilized with her husband's sperm, then implanted into the uterus of the surrogate. All goes well—the

volunteer carries the pregnancy and gives birth to a healthy child—but then she decides she has become attached to the newborn and will not surrender custody. To whom does this child belong?

Case 2: A pregnant woman presents for prenatal care. Genetic screening shows that the fetus is a normal female. However, she and her husband already have three daughters, and he is from a culture that requires he have a male offspring. They request you to abort this pregnancy solely because it is the "wrong" gender. You are a progressive physician who is already doing abortions for other patients who request it. What do you do in this case?

Challenging cases like these happen all the time in the messy real world where clean and neat principles become blurry or even directly conflict. In typical UU fashion, I am not going to try to untangle the issues raised in these cases for you, but instead I invite you to consider them yourselves and discuss with your neighbors at coffee hour.

For now, let's focus on a question that many people have opinions about but not everyone agrees on. When does life begin?

Here are four common answers (and I will not put anyone on the spot here today by asking you to vote for the best answer.)

A) Life begins when a sperm and an egg cell join to create a new single cell that has a unique mix of genes. It now has the capacity to grow and mature in the womb, eventuating in delivery of a healthy baby. This answer—life begins at conception—seems to make sense to many who adhere to Catholic theology.

B) Life begins when a pregnant woman can feel the baby start to kick because that means a soul has entered the fetus. In obstetrics we call this milestone of pregnancy "quickening." This concept was actually part of English Common Law for several centuries. It is somewhat similar to the term "viability" used in the 1973 Supreme Court decision *Roe v. Wade*.

C) Life begins when a baby is born, since only then can it be recognized with a birth certificate, Social Security number, and all the other trappings of citizenship. This traditional definition also coincides with major physiologic changes that happen rapidly at birth, with the baby taking its first breath and no longer relying on its placenta for oxygen. When the baby is born, its umbilical cord is cut, and it starts its own life separate from its mother.

One more definition I have heard is:
D) Life begins when the kids have all grown and left the house.

With all of the tremendous advances in our biologic understanding of pregnancy, many believe that science should help us out with this question and provide the "true" answer. However, the scientific answer is actually "none of the above." Life started on this planet millions of years ago, and in spite of fits and starts of evolution, and many species developing or becoming extinct over the eons, life has never stopped. All organisms alive today came from other living organisms that produced them. So what we are really debating is not "when does life begin" but the question of "at which time in development of a human zygote, embryo,

fetus, child, do we decide to confer personhood?" This is a social and legal question, not one that can be answered by science.

In a while, [Dr. Atif Jensen or Dr. Neil Porter] will discuss issues that arise at the end of life, but before ending this section, let's recap:

Medical ethics is simply a list of principles developed to help medical professionals to behave properly and correctly, even in complex situations.

The four main principles are autonomy, justice, beneficence, and non-malfeasance.

At this point I will close. Thank you for your attention.

Offertory

Preludio de Adios
Alfonso Montes
Zoë Stewart, guitar

Homily

Ethical Issues at the End of Life
(9:30) Dr. Neil Porter

End-of-life decisions are always hard!

In some ways, though, these decisions are less difficult at the extremes of age, such as a one-day old newborn in the neonatal intensive care unit who may have never been held by their mother.

Or the 100-year-old elder who has led a fruitful life, such as Helen Smith, a long-time member of this church.

The more difficult decisions lie in the middle.

The six-year-old struck by a stray bullet; the teenager, just learning to drive; the newlywed; or even the middle-aged mother or father of a twentysomething; or the 60-year-old grandfather or grandmother who has yet to retire.

Death is absolute, depending upon one's religious beliefs.

But determining that death is imminent, or that death has already occurred, can be uncomfortably uncertain.

Medical ethics provides guidance for end-of-life decision-making, with concepts such as beneficence (or doing good) and autonomy (the patients' right to make their own decisions).

But problems still arise based upon the limits of those principles, and conflicts between involved parties, such as disagreements between individual family members, or disagreements between family members and physicians.

Who gets the final say? The advanced directive that clearly states the patient's wishes, or the power of attorney who has been given the authority for decision-making once the patient has become incapacitated?

As medical science becomes more sophisticated and more expensive, end-of-life decision-making may become more complicated if we consider concepts such as distributive justice.

As an example of an end-of-life story that was not an ethical dilemma:

Some years ago I was taking care of a middle-aged man who suffered a large stroke. His wife was always angry and dissatisfied with his care. It was a very contentious situation. Despite the fact that he had had a large stroke, he seemed to be recovering well, and was apparently out of danger.

Suddenly, however, on day four of the hospitalization, he suddenly declined and lost most if not all of his brain function. As the leader of the medical team, I proceeded with a "brain death" evaluation. In the early evening I met with approximately 40 family members to update them on the situation.

Later that evening, after finalizing the brain death evaluation, I again met with the family. Everyone was very gracious, including the wife, who had previously been so angry. She, in particular, now had a sense of calm, probably because her husband had been a man of faith. The whole extended family was comfortable with his passing at that point, and thanked me for my care, not assigning blame.

This was not an ethical dilemma, but what if the family did not accept my findings of brain death, and wanted to continue his care despite that being uncalled for? Or what if the patient had had some signs of life but no chance of recovery, such that continued care would be futile?

These are difficult questions to answer.

Somethings each of us can do, however, include:

1. Making our wishes known to our loved ones
2. Filling out the proper documents as advanced directives and
3. Assigning a medical power of attorney
4. Learning to advocate for ourselves and our loved ones with regard to the medical system.

Thank you.

(11:15) Dr. Atif Jensen

Hi, my name is Dr. Atif Jensen.

I am a nephrologist. That means I treat patients with kidney disorders. Often my patients are elderly and have multiple medical comorbidities that may alter and affect care. Medical ethics is a topic that is definitely near my heart (and kidneys) for that reason. All doctors as they start medical school take an oath, called the Hippocratic oath. I am sure you have heard of it in passing. It is a basic oath that defines our interactions with colleagues, teachers and patients.

Part of the original reads like this:

> I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrong-doing. Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course. Similarly I will not give to a woman a pessary to cause abortion. But I will keep pure and holy both my life and my art. I will not use the knife, not even, verily, on sufferers from stone, but I will give place to such as are craftsmen therein.
> Into whatsoever houses I enter, I will enter to help the sick, and I will abstain from all intentional wrong-doing and harm, especially from abusing the bodies of man or woman, bond or free. And whatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secrets.

So even ancient Greek scholars had strong viewpoints on abortion and euthanasia. Ethics is a fundamental component of a physician's job. Deciding on abortion and euthanasia in one paragraph? That's impressive. Is abortion okay? When is it okay? When is it not? Is euthanasia okay? When is it okay? When is it not?

Only individuals can answers these questions for themselves. Although there are laws and guidelines that help guide these decisions, *i.e.,* euthanasia is illegal, fundamentally we have a concept called autonomy, which is basic self-governance over own bodies.

When it comes to end-of-life ethics, several questions come to mind.

How do you want to die? At home? In an ICU? In a hospice center? If you were incapacitated, what would you be okay with? For how long? Who do you trust to make medical decisions for you? The questions can go on for days, and everyone has their own answers. My belief system as your doctor will likely not match yours. So it's important to understand that patients will exercise their autonomy, as will doctors, nurses, and everyone else on the health care team.

Let's explore autonomy some. Here are a few examples, and so let's see where people stand: Raise your hand if you think your answer is yes.

A Jehovah's Witness needs a blood transfusion, or he is going to die. Can he refuse?

A 12-year-old child of a Jehovah's Witness couple needs a blood transfusion. Can she refuse? Can the parents refuse?

A daughter who is a Jehovah's Witness convert is caring for her mother, who got into a car accident. She needs a blood transfusion. Daughter wants to save her mother's soul, and refuses a blood transfusion. You cannot confirm or deny that mother was a Jehovah's Witness. She is expected to make a full recovery if she receives blood. Do you give the blood transfusion?

So you can see despite autonomy being a pretty obviously ethical solution, it can often become a quagmire of conflicts and deciding whose autonomy is to be respected. These are the kinds of decisions physicians face every day. Thankfully, over the generations we have developed laws to help guide us make these decisions.

The child of autonomy is informed consent. Informed consent is the idea that the patient must be told of and understand the risks, benefits and alternatives to any treatment plan.

An 83-year-old male with severe dementia is no longer eating enough food to sustain himself. He needs a feeding tube, which would give him calories. Should this be performed?

In this case the patient is unable to give informed consent to the procedure in question, so we would have to find someone who can.

Here is another example:
A 90-year-old woman develops pneumonia and needs a tube in her throat to help her breathe. She is currently unable to speak. She has been ready to pass since her husband died two years ago. Her estranged son comes in after not seeing the patient for two years since they had a falling out. He wants to have one last conversation with her to make up. Do you put that tube in her throat?

Ultimately, we like to believe in self-determination and autonomy. This patient is unable to give informed consent at the moment. We want to side with patient. She had expressed her wishes to be allowed a natural death. But the actual legal answer to this question above is more complicated. Who is the health care proxy/next of kin? Is it this son? If so, then maybe the son will be able to keep the patient on life support indefinitely. If no health care proxy is assigned, next of kin is assigned. If there is no next of kin, or next of kin refuses to be health care proxy, then a court-appointed guardian is assigned. Court-appointed guardians almost always do everything, as do doctors when faced with the option of life or death, unless there is clear directive not to.

That means if a 25-year-old gets into a car accident, he or she may end up in a vegetative state on a ventilator for the next 40 years. Whether or not that is for you, it is impossible for me to say. A MOLST (Medical Order for Life-Sustaining Treatment) form is the best way to state your wishes and give informed consent preemptively.

The MOLST form is a form that goes over life-sustaining orders and has to be signed by a doctor. The main question it asks is about CPR. Other questions are asked about dialysis, feeding tube, transfusions, fluids and hospitalization. The more you can answer for yourself now, the easier it is for us to answer for you when you cannot. It is also important to assign a health care proxy that will do what you want—not what they want, so sometimes a very close loved one is not the best choice.

Some medical procedures people should know about:

CPR /DNR: This is the stuff you see in movies. Thumping on chests, giving breaths. Rates for survival are poor, with only 17% surviving at discharge if you (cardio) arrested during a hospital stay, with that rate dropping to 6% over the age of 85. While it doesn't hurt because you are comatose, it can cause broken ribs which would hurt if you wake up. Being down for a long time can cause anoxic brain injury, which means not enough blood to the brain, and can lead to permanent brain damage.

Dialysis: This is a process to clean your blood of toxins and fluids when your kidneys don't work. Doesn't hurt but can be cumbersome if indefinite.

Feeding tube: This is a tube that goes into your abdomen to give you nutrition if you cannot swallow. Doesn't cause pain but can be cumbersome to give feeds. Is especially taxing if you are NPO, nothing by mouth, which means you are only allowed to take in nutrition through the tube. Often this can be very difficult for patients.

Tracheostomy: This is a tube that goes in your throat to give you access to oxygen if you are not breathing on your own and need to be on a ventilator for a prolonged period of time. For the first ten days this tube can be inserted in your mouth.

Transfusion: This is getting blood products from another person. Blood products keep up your oxygen-carrying capacity.

In general, when it comes to my own end-of-life care, I personally have a 72-hour policy. If I don't recover in 72 hours or look like I will recover after 72 hours, I don't think I want to be poked and prodded for longer than that. I can talk to anyone individually if you want to know more about the medical issues involved. I also have several copies of MOLST forms here for everyone to look at and fill out, and you can have signed with your doctor. I encourage everyone to talk about life care planning regardless of age so that your family isn't carrying a burden of deciding what to do in the worst-case scenarios.

Just so you know, the updated Hippocratic Oath is a much better read:

> 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 [that] 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 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.

Thank you for your time.

Stay well.

Hymn

#1031 "Filled With Loving Kindness"

Closing Words

Adapted from The Rev. Carl Seaburg

Between the dawn and dusk of our being, let us be mindful, loving, and brave. In our little passage through the light let us sustain and forward the human venture—in thoughtfulness, in gentleness, and in service.

GO NOW IN PEACE.