

A Doctor's View of Death With Dignity

“When they say ‘Above all else, do no harm’ – to me, prolonging someone’s suffering is doing them harm.”

Transcript of a program sponsored by Hemlock of Illinois on December 8, 2013, in Chicago - with **Dr. Jorge del Castillo, Dr. Dan Fintel, and Dr. Daniel G. Samo.** Moderated by Ed Gogol

Ed Gogol: Ok folks, good afternoon. Thank you so very, very much for coming. My name is Ed Gogol. I am the recently elected president of Hemlock of Illinois. We're a group that has been around since the 1980s. We think of ourselves as being part of the Death with Dignity movement.

Here's how I view Death With Dignity. We're all going to die. And we don't want to rush it. Life is precious. But when we do die, we want to minimize unnecessary suffering at end-of-life. Now, to some degree suffering will always go with the territory. Death is the disintegration of our bodies, and it's not easy. But we want to minimize that suffering.

Now, there's a broad movement for minimizing suffering at end-of-life. Hospice, for example, is part of that. But the Death with Dignity movement really goes beyond the broader movement. We recognize that in some circumstances, suffering is so great that it can be a rational choice to cut your suffering short. To decide not to live through the final stages of your bodily disintegration. Often, this happens when you're near death anyway. But not always. There are other cases - often with neurological diseases - where suffering can be so extreme that it can be a rational choice to cut your suffering short. We call this, "making a final exit."

Our group, Hemlock of Illinois, is part of the death with dignity movement. Three major national groups are working for death with dignity. I'll talk more about this after the main part of the program, but that's what Death with Dignity is about.

Now, we want legal change in Illinois - as there has been legal change in Oregon, Washington, Vermont, Montana and Hawaii. And the movement is on an upswing. And we're just very, very proud and happy

to have you all here: on the one hand because we want to enlist you soon to make this change here in Illinois; but also because we have three incredibly distinguished doctors who are here to speak out and join the cause.

So I'm going to introduce them and then we'll start our panel. On your far right is Doctor Daniel Samo. He is a graduate of Rutgers and of the Chicago Medical School. His specialty is emergency medicine. He worked at Cook County Hospital and Evanston Hospital. Today he is the Medical Director of the Division of Health Promotion and Corporate Services and the Division of Public Safety Medicine at Northwestern Memorial Physicians Group. He is an Assistant Professor of Clinical Medicine and Emergency Medicine at Northwestern University Feinberg School of Medicine. Doctor Danny Samo, on your right [applause].

Sitting on my immediate right is Doctor Dan Fintel. (We have to use the name Dan because that's Danny on the other side.) [Laughter] He is also a Professor of Medicine at Northwestern University's Feinberg School of Medicine. He is an attending physician at Northwestern Memorial Hospital. He's been director of the coronary care unit. He graduated from Yale and from Harvard Medical School, did his internship and residency at Mount Sinai Hospital in New York, and his fellowship in cardiology at Johns Hopkins. He is the author of more than one hundred published articles, reviews, book chapters. He maintains an active clinical practice and professional teaching schedule in clinical cardiology, also at Feinberg. [applause]

And sitting in between Doctor Dan and Doctor Danny is Doctor Jorge del Castillo. He is Associate Head of the Division of Emergency Medicine at

North Shore University Health System, and Associate Professor of Emergency Medicine at the University of Chicago Pritzker School of Medicine. He received his undergraduate degree from Rutgers, and his M. D. from the Chicago Medical School. He did his residency at Michael Reese Hospital and at Evanston Hospital. He's been practicing emergency medicine at Evanston Hospital since 1979. He has served as President of the professional staff at North Shore University Health System. He has served on the North Shore Board of Directors and he is currently a member of the Board of Directors of Northshore University Health System Medical Group. [applause]

Ok, so our agenda for today. We are going to leave plenty of time for questions and discussion. It's a panel. I'm going to toss out some questions for our panelists. We're an informal group, we'll see how the discussion goes. We intend to be done with the program about 4 - 4:15 at the latest.

Okay so let me start. And the first question I would like to pose to our panel is: what were the events, what brought you as a physician to supporting this cause? Anybody?

Dr. Samo: Sure. First, thanks everybody for coming. Probably what brought all of us to this is something that we experienced. So I'm going to start with my vignette, which actually happened to me much later, just several years ago. And it's not a medical encounter. It was my father, who had end-stage heart failure. And then who asked me to help him out. And I said to him, "So what does mom think about this?" He said, "I haven't talked to her."

So my experience was not as a physician, but as a son. As a physician it would be different. If someone came up to me and said, "I want to do this" - they don't need the permission of their spouse. I believe that. But as a son I couldn't just say to him, "Sure we'll do this behind mom's back." That wasn't going to happen.

And part of the reason I'm telling this story is that what I think brings me here is that **there needs to be more open discussion of death. People need to think about this and you need to be prepared. You need to be prepared, you**

need to think about this ahead of time. You need to talk to people. It's all about living wills and advance directives. And it's about discussing this with your friends and loved ones and trying to come to a decision.

The other experience that really brought me here is my wife, who frequently berated me that physicians need to do something, because we treat our pets better than we treat our parents. And I kept telling her, "No it's not really about the doctors. It's really about society allowing doctors to do something - not that they have to do it, but allowing it. Because right now if you do any of these different things we'll talk about, you could lose your license, you could go to jail, you can lose your work, your livelihood." So the fact that physicians do this - either actively or passively, usually covertly - needs to come out in the open also. It can't be behind some closed doors as much anymore. So that's what brings me here.

Dr. del Castillo: He said everything I was going to say so...[laughter] No. So when I met Ed today he said, "Well, why are you here, what made you come here?" And I said, "Jeanette Samo made me come here, otherwise she wouldn't invite me to her house anymore." So here we are. Danny and I go back a long way. We went to college together, we were college roommates, so we've had conversations such as this over the years many, many times.

And I have a similar anecdote, where I had a 96-year-old aunt who passed away last year. And she was clear minded, sharp as a tack, but had heart failure. She just wasn't getting around anymore. She wasn't enjoying life. And when I went to Miami to visit her, she approached me and said, "You know you really need to kill me." That is exactly what she said. I said, "Wait, I can't do that. You know you're still around, we're still enjoying each other." She says, "Yeah but when you leave I just don't enjoy things."

Now needless to say she died a week later. I think she willed herself to die. But nonetheless it was a heartbreaking situation for me because I maybe had the wherewithal to help her but I could not. So I think, like Danny said, we really need to move forward and get our legislature involved in making

some progress in this state and nationally. We are a significantly civilized society - we think. There are other countries that have far, far better systems than we do. But I think we need to make some inroads.

The other thing I want to tell you is that we need to talk to each other - and doctors need to talk to patients. And if your doctor doesn't talk to you, you need to talk to your doctor and you need to make him or her talk to you. And you need to be prepared. I'm an emergency physician and I can't tell you the number of times that I've had an individual arrive at two o'clock in the morning, dying without any advanced directive - or a DNR [Do Not Resuscitate Order], if you will. Or they had an advanced directive at their nursing home that was just never set forth in the record, or they didn't pay attention to it, or they ignored it, or any number of other things. So they panicked and they called the ambulance. And that is a very unfortunate thing, because not only are you using a lot of resources, but secondly you are really not dying with the dignity that you should. So that is one of the key things that you should take away from here.

I think you really need to talk to your doctors, you need to talk to your family, and you need to be prepared for when that time comes so that you can actually exit with dignity. Because you may not have the ability to control that situation at that time. Dan?

Dr. Fintel: Thanks, Jorge. We're also thrilled, the four of us up here at the table, that so many people have taken time on this snowy afternoon to come share your vision and ours as to where we can be going in the state of Illinois. Before I tell you my very memorable story, please just by a show of hands - How many of you have personally experienced in a family member a painful, difficult death? I see eighty percent of people raised their hands. How many, on the other hand, have been fortunate enough to experience a peaceful, tranquil death of a family member - it may have been natural, it may have been assisted in the hospital? Less hands go up, maybe about ten or twenty.

This is a problem we all deal with. And the example I want to share with you comes from my experience as a critical care cardiologist. I've been very active in the CCU at Northwestern, in fact I finished rounds at eleven this morning, I'm on duty now. [laughter] And I was a newly minted cardiologist, a little thinner than I am now. I think I was around 37 or so, I was four or five years on the faculty at Northwestern. And I had come to manage a lovely elderly lady who was 82 when I met her and had significant heart failure. But she had quality of life and a loving family. And about five years later it was clear that she was deteriorating. And she was getting the best medical therapy we could offer her. But she was drowning in fluid and had had several admissions to the hospital for heart failure. And we would dutifully give her diuretics, reduce her fluid, get her home. But she was very fatigued, and finally she was leading a bad existence. She really couldn't get out of bed. And she and her daughter had shared with me the fact that they thought the end was near. Was there anything I could do to assist them in ending her life peacefully?

Nothing in my training at very elite medical schools and hospitals had prepared me for the kind of advice I was being asked to give her, the treatment I was being asked to give. And I suppose what I did that day is certainly not the kind of treatment we are speaking about in the laws that have been passed and so successfully implemented in states like Washington and Oregon. But I asked around among my anesthesiologists, and I acquired a fairly large bottle of an oral version of morphine that we give cancer patients appropriately to help ease their pain. And I calculated the dose with my anesthesia colleagues, because I didn't know it as a critical care cardiologist. And I explained to her daughter how she could drink that dose and then pass away very quietly. And that's exactly what happened. And the family was very grateful. And I felt very good about what I did, but I didn't write it in the chart or in the medical record. I signed her death certificate as a death due to heart failure - which it really was. But that was my introduction to what I can do as a critical care physician outside of the environment of the hospital. And I just give that as an example of the kinds of things physicians can do. It's not exactly what we're talking about today, because that was an

individual act by me in a circumstance that, you know, was very, very new for me. But I wanted to give that as an example.

Ed: So in the spirit of seeing where the discussion goes, that makes me think... So ok there are living wills. There are DNRs. There are physician's order for life-sustaining treatment. There are durable powers of attorney for healthcare. As someone with my share of experience in the medical system and taking care of ill friends and relatives, I've always been skeptical of those documents except possibly the durable power of attorney for healthcare. Do these forms actually... do they help? Do doctors read them? Do they succeed in conveying wishes? Tell us about those forms and which one of those forms people should really have, which ones are important?

Dr. Fintel: I can start. As an inpatient physician I can share with you what we do in our hospital. Two of us are working at Northwestern, and one of us is formerly at a Northwestern institution that is now a part of the University of Chicago. When patients are admitted to the hospital - as part of their questions from the admission office - there are specific questions as to whether a living will exists. And a living will is offered to the patient on admission. Or if there's a durable power of attorney which had been enacted and that's duly noted in the medical record. That doesn't mean we have a copy when we manage the patients, but we know one exists. And I can tell you that our newly trained doctors, interns, and residents that are being trained in hospitals throughout the country, that they are more aware and sensitive of this issue than I think any of the three of us were during our period of training in the '70s and '80s.

And it is noted whenever a patient comes into the intensive care unit. I work in the coronary and medical intensive care units - if a patient has a living will it's noted. If a patient has a durable power, the person to whom that durable power of attorney has been granted is generally indicated on the medical record. So that helps us. It doesn't solve all the issues, but at least establishes a communication pathway that allows us to make more rational decisions.

As Jorge mentioned - and I'm going to give him the microphone now - working in the ER can be very, very challenging when patients come rolling in and those papers are not available.

Dr. del Castillo: Thanks Dan. Ed, there is a lot more tumult in the emergency department, and especially at night in the off hours where you can't reach anyone. You can't reach a physician, you cannot reach a family member, and consequently if that form is not with the paramedics... I mean, they'll say, "Well we didn't see one, we didn't find one." Which is why I exhort you to, if you have a relative yourself and you're of sound mind to make sure that those forms - the i's are dotted, the t's are crossed. Everything is in order and that you have those ready right there by your bed. We joke often in the medical profession, when we see bad cases, some of the nurses and doctors say, "Well I'm going to go to the tattoo parlor and have a DNR tattooed on my chest. When I get to the emergency room and they open up my chest then they'll see and they'll know what my wishes were - with my signature." And it's sort of black humor, but it's true. I mean people are very, very concerned that their wishes are going to be ignored in the hour when they really want to exit with some dignity. So again I repeat that that is extremely, extremely important to make sure that all these things are ready.

To your question though Ed, I think **the papers definitely work if they're in order – and all the circumstances are right.** If you are in a neighborhood where you reside, or where you're in the nursing home, or your loved one is in a nursing home, and you're going to a particular institution - whether it be Northwestern or Masonic or Evanston Hospital makes no difference - and you have a chart and a doctor there, generally if you have made those wishes on your advanced directive, this will be noted right on the electronic medical record. It will say, do not resuscitate, or, I have an advance directive, whatever it is. And it's in there and when the chart is picked up, immediately the individual physician will know and the staff will know. But you don't even want to get to that point. **You really want to exit prior to that, in a more dignified way than getting into an ambulance and having**

all sorts of things done that you really wish were not done. Your turn.

Dr. Samo: I think you guys covered it.

Ed: I have my spouse, and I hope she will respect my wishes and what the durable power of attorney says. That document vests in her the power to make medical decisions for me should I be unable to. It also might say something like, if my heart stops I don't want to be resuscitated. But do the doctors actually look through the documents for those specific elections, or is it more just specifying who has the right to make those medical decisions?

Dr. Fintel: Well, with a living will - which is a simpler document as I understand it, and I'm not an attorney - that basically states that I do not wish measures to be provided to me that will prolong my life if there is no meaningful chance of a recovery. That's usually very clear in a living will. It's a more straightforward document. But as we all know there are profound subtleties in medical care in which patients are critically ill, and it requires a great deal of insight into the patient's disease, into the severity of their disease and what treatments are available, when truly there are not measures available that can prolong life for an extremely long period of time vs a short period of time. So these can be very complex decisions. The durable power vests the power to make those decisions in a family member - usually family member, or maybe a friend. The document may or may not specify under what medical circumstances the designee of the durable power will make those decisions. It really depends on how the durable power is written. And it means you've determined that the person you vested the durable power in knows you and can make those decisions on your part. But there is a great deal of education and decision-making that has to be made between the person granted the durable power and the medical team in deciding how long to prolong life in say a comatose, intubated patient in an intensive care unit or a patient with end-stage neurological disease. So just having a durable power doesn't solve the issue. But at least it makes the decision-making clearer, in terms of who is designated to make it.

Dr. Samo: And in practice - especially in the emergency room - if the spouse is there and the patient is unable to talk for themselves then we're going to go to the spouse. Or a child. But other than that, if you want someone other than that to be your representative, you'd better have that clearly written and with you. Because otherwise, someone says I'm his best friend, or I'm their roommate, or I'm their lover - it's not going to fly. Really, beyond spouse and children it gets a lot trickier.

Dr. del Castillo: And you know, one of the problems that we encounter is that regardless of there being an existing form, is that an individual family member - and I am sure some of you been exposed to or have heard of these situations - will object. And will say, "Oh well you know she really didn't want to die. She didn't really mean it." Or, "He wants to be around for a longer time," and so on. And so you have the sister from California and the brother from Joliet arguing over the phone with the doctor about whether you're going to do something about this or not.

Now, unfortunately for Dan, he lives with this a little bit longer than I do. In the emergency department, we deal with the situation, we stabilize it, and then the patient goes up to Dan in the ICU. So he has to deal with it the longer term. For me, I've tried to solve the problem in the locale where I practice. And the person either succumbs or is alive. We resuscitate him, unfortunately sometimes, and they go upstairs to live for another day, week, who knows how long.

So to your point I think you really need to make sure that these things are very, very clear and who you want and what you want.

Ed: Okay, so let me switch gears here and dive right into the subject of the Oregon-style Death with Dignity law. In Oregon, the law was first passed about fifteen years ago. Then it was passed a second time in Oregon. There's a similar law on the books now in Washington, and also in Vermont. Basically, the Oregon law says: First of all you have to be adult. You have to be mentally competent; you can't have dementia. You have to make a request - I think it's at least two times, maybe more. One request has to be in writing, so you know it's

not an ill-considered decision. Your doctor and another doctor who is not your primary doctor have to agree that you have less than six months to live. And if you fit all of these requirements, then your doctor can write you a prescription for barbiturates. Now, your doctor is not obligated to do this. If you have an unfriendly doctor, you may not be able to get this to work. But if you have a friendly doctor, the doctor will write you a prescription for a lethal dose of barbiturates. And you literally send your spouse or yourself off to the drug store, and you get a package and it sits on the shelf. And then if and when - if you feel your suffering has become intolerable, you basically mix this stuff up and drink it down and you go to sleep.

That's the Oregon-style law. **And the key, the essence of the Oregon-style law is that it protects the patient and it protects the doctor. It explicitly says that your cause of death wasn't a suicide. Your cause of death was your underlying illness.** And every step on the process is prescribed, there are forms at every step, every step is reported to the state health department. They collect a lot of evidence. It's been a tremendous success, we think.

So I'm going to cut right to the chase and ask our panel what do you think about these laws? Would you support the passage of such a law in Illinois? What would you like to see changed or different or added to it?

Dr. Samo: The first question is do I support that type of law? Yes. And I think when we talk about this, everybody needs to separate very clearly in your head the difference between this and what is called physician-assisted suicide, I mean there are all kinds of different names. But **with the Oregon law, it's a competent person who takes the medicine by themselves. The physician doesn't administer the medicine, the physician doesn't give an IV. It's not done by the physician. The physician writes the prescription, but does not administer the drug.** Which is a different scenario from an incompetent person and that's a whole different

topic. And that's not what this is about. This is about a competent person who decides, it's time and I want to go. And I'm for it, personally.

Actually it's an interesting disconnect between the general population's attitude about this, and doctors. In the most recent polls, anywhere from sixty to seventy percent of people are in favor of having a law like this, whereas sixty plus percent of physicians are against it.

So it's a real disconnect and the reason... actually when you delve into some of the positions, drill down in the questionnaires, a lot of it is about religious reasons. But the other argument for physicians being against it is that physicians say that our job is to heal. Our job is not to kill people, it's to heal people. It's to keep them alive, to give them hope. And provide that hope. And so they feel that that is against what they do.

Now personally I find that a little disingenuous. Let's go back to my example of my father. The physicians, the palliative care doctors told my mother, "Now if he's having trouble breathing, give him more morphine." Now excuse me, if you're having trouble breathing, morphine is the wrong thing to do if you want to keep somebody alive. If you want to help them die, that's the right thing to do. And so really they were saying to my mother, "Here. You do this. This'll kill him. When he gets that uncomfortable." So there's some disingenuousness.

The other thing is that physicians, you know, in one poll 66 percent said they are against physician-assisted suicide, against having someone write the prescription. Yet I think it was only 25 percent were against what's called terminal sedation. Which means that someone's terminal. You put them into a coma, a medication-induced coma, and you let them die. Now how is that really different from writing a prescription? So a lot of it is in the semantics of what goes on, and I think that as we have more discussion, attitudes are changing. Certainly in the public the attitudes have changed. I think physicians' attitudes are starting to change too. But I think again that we need to have these discussions. And people need to let their doctors understand that they want this. And so, I'm for it.

Dr. del Castillo: Yes, despite the fact that we may be in agreement with these laws and we would like something passed to ease the burden on us and society, physicians are significantly conflicted with doing some of these things.

On one hand, we don't want our individual patients to suffer. It is an incredible emotional burden, especially in long-term care.

For me, it's episodic, but still, you know you see families historically having an individual suffering and coming back to the hospital over and over. So yes we are conflicted. And in fact the Hippocratic Oath basically says you will not give a lethal dose of any medication to a patient who asks you for it. Among other things, that's the Hippocratic Oath, which we all took. So again, not only did we take an oath that we would not do something like this, but we are conflicted about it.

Nonetheless, with regards to some of the anecdotes that have been brought forth today, I have one very similar to Dan's. Which when I was a resident I had a little-bitty lady who had esophageal cancer. And she was suffering, it was terrible. Every time you see her, she would be wilting away in the hospital. And I asked the attending physician - I was an intern, I was first year, I didn't know anything - and I said, "Can we do something to help her out?" And he said, "Don't worry, I'll take care of it." And I went to the operating room that night and I came back in the morning to see her and she was gone. And I said, "What happened?" And they go, "She died." Well I looked in the orders and of course what he had done was what we called the double effect, when she was in a lot of pain, administer morphine. And mind you this was in 1975. Administer a significant amount of morphine that this lady could never tolerate and she passed away peacefully in her sleep. So are very many physicians out there, despite - and I'm very surprised at those statistics. 60 percent, wow. I didn't think that...

Dr. Samo: That's what they say.

Dr. del Castillo: So anyway that... well right that's what they say as opposed to how they act. Physicians really are on the patients' side. But understand that we have not only personal conflicts

based on our oath and profession but also, you know, legally we have significant legal concerns.

Dr. Fintel: In addressing this question I want to begin with a little bit of statistics. How often has this form of dying been implemented in states that have these laws on the books? It turns out extremely infrequently, and I think attesting to the tremendous safeguards built into the legislation Ed shared with us. For example in Oregon and in Washington that have had these laws on the books for fifteen and five years, respectively, roughly about 0.1 to 0.2 percent. Or spoken another way, 1 to 2 out of 1,000 recorded deaths in those states have been deaths in which patients have received medications that have been prescribed to end their lives as per the definitions of the statutes on the books in those states. **So this has not been an abused treatment. This has not been a wholesale reason for people to end their lives early because their medical bills were horrible or family members wish to do them in.** That was a real concern when those laws were written, that there would be tremendous potential for abuse.

Now as Ed shared with us, having two doctors - one that is intimately familiar with the patient and one who has been asked to review the situation - is not an absolute safeguard. But we all take our Hippocratic Oath and it would be nearly inconceivable for a physician to affix his or her name to such a prescription for a high dose of barbiturate, for example like Seconal, without having carefully considered those medical implications. And to reiterate what Ed said, a patient can't receive this prescription just by a visit in the office and having two doctors approve. They have to request it two separate times, so that may be a two week or four week hiatus that they have to return to the doctor and make that specific request when they're very awake and alert.

So there are safeguards. There are no absolute safeguards in any treatment we give, but there are safeguards built into the legislative systems in states that have enacted them that help ensure that the people who request this type of final exit do so after careful consideration by them, their families and the medical professionals entrusted with their care. So

this is not something that has been widely implemented - even in states in which it is available.

And there has not been a socioeconomic basis for this treatment. There were some concerns that indigent people who suffered much greater financial penalties from their life-ending diseases would use this as a way for families to end the horrendous medical costs that they were experiencing with end-of-life care. The available research has not supported that conclusion either. So initial available results are all very encouraging - that this has been very appropriately implemented, as of course we would all wish for our patients.

Dr. Samo: What Dan was talking about, the objections to this, there was a European task force that came up with six things. And one was that this would worsen the quality of palliative care. And that's often an objection you hear, is that you know these people if you really got them proper palliative care, they wouldn't really need or want to die. That we physicians with palliative care can really take care of everything. Which is probably not true. But the Oregon experience really showed that spending on and discussions about palliative care increased significantly with the law. So it turns out that that concern was not true.

The other one Dan touched upon was discrimination. That lower socio-economic people, people of color would be discriminated against, and it turns out in Oregon it's mostly white upper middle class people, educated with bachelor's degrees or higher who do use the law. So that didn't turn out to be right.

There was the slippery slope argument, that this would lead to expanding the scope of who's going to be allowed to ask for the medication. And in Oregon's experiences in fifteen years, it hasn't changed. And it really is not expanding.

Abuse questions - again Dan touched on that - unscrupulous relatives, you know my kids want to do me in because they want to get my inheritance - (you don't get it that fast, trust me) - has also not happened. I mean Oregon's great, it's like a social experiment that's really long-term now. A lot of these concerns have been answered.

And then there's two others. The last two are that assisted dying undermines the sanctity of life. Now that's not a factual question. That's an ethical, moral, religious, personal issue. **The big thing is this is about your personal autonomy. This is your choice. Nobody else is involved in this. This is your life. There's not a pregnancy involved. We're not talking about doing it to somebody else. This is my autonomy, my choice. If your religion or your beliefs say you shouldn't do it, you don't have to do it.**

And then there's the objections of the medical community which I talked about before. And one of the interesting statistics is that I think it was of the 1,100 prescriptions that have been written in Oregon since this started, only a little over 600 of them were used. So a lot of people who get the prescription don't use it. You know, sometimes I have patients come in with injuries, and I say, I want to give you this prescription for narcotics, you know so if your Tylenol or Advil doesn't work you have it. Most of them don't fill it. They're very comforted by the fact that it's there. So if I need it, it's there. And that seems to be the same experience here.

Dr. del Castillo: Again referring to my experience as an ICU physician, it's much easier for us to implement these actions in the hospital because we have critically sick patients. They're on respirators, they're often comatose. When we have the luxury of a durable power, a family member or a clearly written living will, it's ... I hate to say the act of dying is ever made easy, but it's very easy to implement these decisions by extubating the patients, increasing the degree of sedation so that they have no air hunger, they don't fight the removal of the breathing tube. And they pass away very quietly.

So in the hospital we have systems in place to allow us to help patients with the dying process when it's clear that they're beyond any reasonable hope of meaningful recovery of consciousness and a normal lifestyle. It's really when patients go home and

continue their suffering at home with chronic debilitating neurological illness like end-stage muscular sclerosis. I'm sure there are people in this audience today who have family members with that horrible disease. Or end-stage cancer with the terrible pain and disability that end-stage cancer brings our patients. Or end-stage cardiovascular deterioration where patients are drowning that we really need the help as physicians of the legislation that can - again following the appropriate safeguards we're talking about - allow us to allow patients and families who wish this process of ending to do so in a humane and medically appropriate fashion.

Ed: So you make me think hard about the contrast between... well for example I'm thinking about the movie, there's a wonderful movie - we'll do some more showings of it. It's called How to Die in Oregon. And it profiles one of the patients, Cody Curtis was her name. She had I think liver cancer and she survived with it a long time and you know she was relatively young - I think she was in her fifties. And so she chose to use the Oregon law not to go through the final stages of her bodily disintegration.

So let's contrast that situation. Let's say an elderly person and maybe they have cancer and it's agonizing. Or maybe they have heart disease, and they are drowning in the fluid, etc. You know, you're getting progressively more and more debilitated. As physicians, it's perfectly ethically acceptable for you to administer medication that will relieve suffering, even if this hastens death.

I don't know, maybe you can't answer this... Well, I'm going to ask you to answer it. How often when you do this are you... I mean is it often the case that you know that in reality this will hasten death? Are you primarily relieving suffering or hastening death? What are the situations that lead people to be put into terminal sedation? And are there some hospitals - are you are you better off if you get lucky to be in this hospital versus that hospital? [laughter] Other than Evanston.

Dr. Fintel: Well I want to start by saying where I practice was fortunately evaluated as one of the top ten hospitals in the country. But at Northwestern, like at any good hospital, we have systems in place

to be able to allow patients to die peacefully in the hospital. And it's often in our palliative care units or in our intensive care units when there's been agreement by the patient - if the patients can be part of the decision or by their family members who are designated with that decision to do so - and I just gave some examples a few moments ago how we do so.

Lots of patients who get sick in an ICU have a breathing tube down their throat and a ventilator breathing for them. And the way we most often help patients end their lives in that circumstance is to disconnect the ventilator and use aggressive doses of medications that both dry secretions - so people don't drown in their secretions, which is an involuntary response of the body when breathing is inappropriate - and to get rid of the air hunger that occurs when you can't breathe but you have a sensation that you need oxygen. **With the medications that can be given, patients can pass with a great deal of dignity and no suffering in an hour or so. And that's done on a regular basis in intensive care units.**

Dr. del Castillo: Yes, absolutely without a doubt. And in fact I think you ought to know that palliative care has come a long, long way. I mean there are fellowships across the country now. At the University of Chicago, at Northwestern. Palliative care fellowships where individuals from... physicians from internal medicine that - I have a colleague in emergency medicine who is actually doing a palliative care fellowship now. And they very much direct themselves to a final exit or an easy exit. And they have refined the way that people can exit gracefully and with dignity as you mentioned before.

The other thing with regards to medications - and again Dan has touched on it a couple times and I mentioned this, the double effect. **One thing that the double effect means is that you are palliating somebody's pain with a narcotic, such as morphine. But at the same time, if you give enough of a dose, that medication has a double effect - a double effect meaning you will stop breathing.** Whether

you do this at home, whether it's done in a controlled setting in the hospital. But these things are being done by physicians right now.

The main thing is actual agreement and communication between you and your physician. And not only between you and your physician but your significant other as well. I mean everyone has to be on board so you can progress to the next step without being hindered by legalese or all sorts of other problems that we encounter nowadays.

Dr. Samo: And also Ed talked about how this is mostly... we always think people are doing this because they're in horrible pain. And again Oregon gives us some interesting data. The top reasons for asking for this? Number one is loss of autonomy. The inability to really care for yourself, to do for yourself. A loss of ability to perform your daily activities. A loss of dignity. Loss of bodily functions and being a burden on your family and friends. All those reasons were reasons that were cited by people that got prescriptions as the reasons for wanting the prescriptions, before pain. Pain was only about twenty five percent of the people. And then less - about three percent of people - cited financial reasons. So there are lots of reasons other than horrible pain that people are looking to end their lives. And I think with the proper safeguards like Oregon's law does, I think that that can be appropriately chosen.

Ed: So let's say it's twenty years from now and attitudes have continued to progress. People are much more cognizant and aware of all of these issues. There are Death with Dignity laws on the books of almost every state etc. Do you still think that the usage of those types of laws will be relatively rare or will it be much more common? As opposed to the more peaceful, it's just your disease progression, you reached the point, the doctor increases your morphine dose.

Dr. Samo: I think it will continue to remain rare. As Dan said, less than one percent of deaths. We all sit here now and we say, "Oh if I ever get to be like that, you know, put me away, give me the shot. Do whatever it is you need to do." It turns out when you study people, when they actually get to that point or some point along the way, attitude changes.

As I said, almost half the people who got the prescription never used it.

I think it's not something that people want to do. I think most people want to continue to live. There's often an attitude that I can't do what I did when I was twenty...but you want to take joy in what you have. And this is the lesson again from my father - some people see the glass is half full, some people see the glass as half empty. My father was not a half empty person, he was, "Look there's a sip left in that glass. Let's enjoy it." And I think that's what most people come to. So I think the answer is, it will probably still remain rare.

Dr. Fintel: I agree.

Ed: So I'm in the hospice. I'm suffering or my loved one is in the hospice and suffering. Do I need to be more aggressive in asking for the morphine? Are there cases where not enough is provided without the patient or the patient's family really asking for it?

Dr. Fintel: I'll begin an answer to that, starting from my own personal experience - in my family and that in my professional experience with patients that I've sent for hospice care. My mom passed away about three years ago of end stage lung cancer after a five-year struggle with the disease, which in the last few months of her life left her a pulmonary cripple, extremely ill and knowing that the end was very, very near. And my brother and sister - my sister's here in the audience - involved a hospice program associated with I think Northwestern Hospital who came... the hospice nurse came on a daily basis to her new home in Glenview and sat with her for many hours a day. And administered appropriate doses of morphine for the first day or so to establish what her needs were for analgesic medication. And by the third day my mother had already made her decision, which we certainly supported - that that was going to be the last day of her life.

Then the hospice nurse determined the - my mother was a former nurse, a midwife - the appropriate doses that were needed to end her life peacefully. And I got a call - I was seeing patients that morning.

My kids came as well. My nephews and nieces came. The end was within several hours, and she took several oral syringes of the morphine until she lapsed quietly into sleep and passed away. And that was using I think the hospice program supported by a physician who must have written the order for it - it wasn't me of course - in the most appropriate way. So my mother was able to manage her dying process in the most humane and dignified way imaginable.

We've been able to work with our patients in appropriate hospice programs to establish a clear goal of care. That's a little different than what's indicated in the legislation we're talking about, but the purposes are absolutely the same - to identify the means of treating suffering and allowing a very peaceful exit.

Dr. del Castillo: Yes I absolutely agree with Dan. And to your point Ed: I don't think you really have to be - I'll guess maybe the word is "pushy" with the hospice and palliative care people. They are very... I mean, that's what they do. And they're very, very cognizant of the needs of patients as they exit gracefully or try and help people exit gracefully.

Sometimes the family needs to understand what the picture is all about. And I think it's just a matter of communication between the physician, the palliative care nurse, and the family as to what is going to happen. Just set a stage for what is going to happen in the next day or so. And I don't think that there's any reason for pushiness. These people know what they're doing in these days... at least in my opinion.

Dr. Samo: And the other thing of interest here is... We keep describing people having all this morphine and they take it and they die peacefully. **But doctors are saying in their surveys, "We're not going to give you a prescription for barbiturates or pills that you're going to take that are going to kill you. But I'm going to give you this morphine - wink wink - for your pain." So that's some disconnect I think between what doctors are doing and what they're saying.**

Dr. Fintel: Danny, you told us earlier about how many physicians oppose a very specific act of physician-associated end of life. Do you have a sense that our young doctors coming up in training programs today have a different perspective? I don't know the answer. Do you know of any poll information that suggests an age difference - in old farts like us who are in their sixties vs. physicians who are in their thirties emerging from their training programs? We are enlightened old farts, I would add. [laughter]

Dr. Samo: We are enlightened, yes. There was... I think it was a trend towards younger physicians being more open to it. But not significantly. And it certainly... it broke down along religious lines a lot too. A lot to do with whether you are for it or against it.

Dr. del Castillo: Dan and I were having this conversation earlier, and I think that physicians... the younger ones are more in tune than how we were 30, 35 years ago during our training. Our training was directed at medicine and that was it. And death came, but death was the enemy. It still is, but I think physicians nowadays - the younger ones - are really more in tune into a better lifestyle for themselves and for their patients.

Dr. Fintel: When I take admissions in the CCU, as each patient is presented, one of the things that is always included in the admission presentation - and again, I work in a critical care unit with critically sick patients - is what the patient's status is regarding resuscitation. Whether a durable power of attorney is present. That would never have been part of my presentation when I was an eager beaver medical student in 1978. But that is now standard in the approach of our medical trainees - to at least inquire and to begin to learn about these choices.

I have a daughter who is a medical student here in the back and she told about some of her coursework - where I'm on the faculty at Northwestern. Students have specific instruction in issues of palliative care. They have specific instructions - or teaching rather - in issues of end-of-life decision-making. Again, that would never have been part of our training when we were in medical school.

Ed: Ok. Hang on folks, we're almost at the question period. I'm going to switch gears and talk a little bit about the movement and the cause and Hemlock of Illinois. And then we'll dive into the question period.

So there are three major national groups that are focusing on this issue. They are called Compassion and Choices, Final Exit Network and the Death with Dignity National Center. Our website at www.hemlockofillinois.org has links to all three.

You may ask, "Why three?" Well it's complicated, but they all have a little bit of a different approach, and they all do different things. And they're all wonderful. So I would recommend for every single person in this room: send a contribution to at least one of these three groups. And probably better... maybe you decide long term you only want to support one of them, but at least one time, send a contribution or join all three of them. They're all wonderful.

Our local group, Hemlock of Illinois, which has been around for quite a long time - a number of decades - is an affiliate of Final Exit Network. I think of Final Exit Network as the most radical of the three groups. Suppose you don't live in a state where this is legal, or even if you do, but you don't qualify for that situation. Maybe you have ALS or...you can be suffering interminably and not terminal. Final Exit Network's trained and compassionate volunteers will come be with you and support you and help you through exiting. They never physically assist but they provide a compassionate presence and make sure things go well. And they tell you how to do this, even if you can't get barbiturates, etc.

So again, I recommend that every single person here join one of the three groups. Or even better, all three of the three national groups. If change is going to happen, these organizations need to be strong and need to grow. The other thing - and ok colleagues get those baskets out. Ok so if we are going to make change right here in Illinois... You know, it took us a couple thousand dollars to put on this program. It wasn't much. We ran ads on WCPT, on WBEZ. We did mailings etc. We want to keep doing it. We want to run ads, we want to do mailings, we want to make things happen. You know, we don't have any staff, we run close to the

bone... If you look, for example, at the scale of the effort that brought about marriage equality in Illinois, it was big. But **if we're going to make change in Illinois, we have to get a lot bigger and a lot more well-funded and a lot more organized than we currently are. And we intend to do that. But in order to do that we need funds. So please, dig into your wallets. Contribute generously.** You can do it now or you can do it after the fact - drop us a check. Use PayPal on our website. We take credit cards and I'll be happy to take your credit card after the program. So again please, if we're going to do this - and we're doing it for ourselves and our loved ones, as well as the broader society - **we need all of you.** And we're a volunteer group. If you would like to become more involved, we need more people to become part of the circle of activists and there's a lot of individual things that people can do.

So come talk to some of the board members who are here: there's Ken Leonard in the back; Connie Bezanis; Sheila Riley; Joan Sophie; Deborah Scott; Deborah Landis; Edward Schneidman. Our past president who is very active in the national Final Exit Network, Rosalie Guttman is here. So please, please join us. Ok, very, very important.

Ok, so let's dive into questions.

[Speaker - question]: In Sweden, I think the Netherlands, Sweden has some similar laws. Do you know the type of law and do you agree with it - the panel? And thank you for coming you guys, thank you tremendously for coming. [applause]

Ed: Thank you panel. I'll say one thing about that. One of the things that Danny, that you were talking about... I mean, I try not to use the term suicide. **I try not to use the term physician-assisted suicide, even for an Oregon law, because a physician might be writing a prescription, but still I'm drinking the stuff down.**

In the Netherlands and in Belgium they have "euthanasia." What we're talking about here is not euthanasia because it's not something that's done to

you, it's something you do yourself. But sure, talk about the European experience. Talk about euthanasia. Talk about Holland if you want to.

Dr. Samo: I don't know a lot, but I think Switzerland actually has a program called Dignitas. And yes, it's a very, very different question. Whatever we want to call it - PAS vs. euthanasia. But in Europe, they're not that far different from what we're doing. It's not like they're light-years ahead of us or anything in this - or behind us. It's a judgment call. But I know in Switzerland it is legal, and in the Netherlands also. It's the same sort of surveys - it's still sixty, seventy percent of the people think they should do it.

[Speaker - question]: I had an experience a decade ago or so. I was the agent under a power of attorney for a secretary in our office. She became ill and was suffering terribly and was in the hospital in Evanston. She wanted to end her life and she... she needed to end it. I asked the doctor, "You know, I am the agent under power of attorney. Let's do what we can. " What was very interesting was that that hospital had a policy of not honoring your power of attorney. Legally there is no requirement that the power of attorney must be accepted or honored by anyone it is addressed to. You don't have to do that. And what I learned was you have to be thoughtful ahead of time. Talk to your doctor. See what his thoughts are on this subject, and then the family needs to know where to take you - which hospital if something happens you. Because what we don't know is that powers of attorney do not have to be honored by anyone that is approached by the agent under the power of attorney.

Ed: I don't believe legally that is correct. I think if you have a...

[Speaker - question]: I'm an attorney and that is correct. That is correct.

Ed: I think we'll agree to differ on that. I imagine there are many situations where they are not honored and it can be a struggle. And in that vein, if you're in that situation - come forward. Give us a call or call the American Civil Liberties Union, because we need to push these things.

Dr. Samo: But also as a physician, you don't... You can't be forced to do something that you don't want to do. Same with abortion, anything. You say, "I want you to end my life." I say, "I don't believe in it." You'll have to find somebody else. And I think you are talking about... not the good hospital in Evanston, the other hospital right? [laughter] I just had to stick up for him, you know. I mean obviously you know religion becomes a big part of why that exists. And that also becomes the thing when you decide where you want to go, think about what philosophies the hospital may have.

Dr. Fintel: I addressed your point a little bit earlier but not with the starkness that you brought to this awful issue. And I used to play baseball near that hospital as I grew up in Evanston. [laughter] So much depends on how the physician team instructs the family, and in your case, you as the person granted the durable power of attorney. If the physician team feels that that individual is going to survive and has a modest chance of benefit, it is the physician team's responsibility to share that with the person who has that durable power of attorney. And to state that medical therapies are still available to treat that individual and perhaps that's where, you know, the situation occurred with your secretary's end-of-life illnesses. And there are circumstances when we know that we can improve someone's cardiovascular instability and get them to a point where the tube can be removed and they can breathe on their own and ambulate on their own. And those are difficult issues and you need the advice of the physician team. The person with the durable power of attorney is usually not a physician, and even a physician may have a slanted attitude towards survivability. And it IS our responsibility as doctors to provide the very best advice we can about survivability and the quality of life following the medical intervention for that person. My guess is that is where some of the differences may have occurred in that case.

Ed: Right, but you as an individual will always have the right to refuse medical treatment if you don't want it. And if you are not able to make that decision, the person who has your medical power of attorney has the right to make that decision. The national group Compassion and Choices does a lot of

legal work in cases where people had trouble having their wishes respected.

[Speaker - question]: I wanted to say that I was so happy to hear you mention the American Civil Liberties Union. Because this really involves the issue of the right to die. You know it's not suicide - it's the right to die. The other thing I wanted to mention: I wonder if you're doing any work to see about amending the Hippocratic Oath... [laughter] [applause]

Dr. Samo: I don't know, it's in Greek. [laughter] That was Dan's thing. I don't think amending it... It's like all the things from thousands of years ago - the Bible and Hippocratic Oath and all the things. You can read into it anything you want. And so when it says "Above all else, do no harm" - well are we doing harm by prolonging suffering? So it's really... it's about interpretation. Not about the words themselves. And I think that as our attitudes change... Now words are important. But you know, **when they say "Above all else, do no harm" - to me, prolonging someone's suffering is doing them harm.** If they don't want that, alright. If they say, "I want it, that's ok. I know I'm suffering but I want to keep going" - that's their choice. But not my choice. So I don't think we're going to change the rules or the vows.

[Speaker - question]: I'm thinking about this from the policy perspective. And one of the things I've observed is how difficult it is - particularly for older folks who may not have people who are really paying attention and taking care of them - sometimes we don't find their durable power of attorney. We don't know what their wishes are. Is there any policy drive to get a statewide or national registry so you don't have to have it in your freezer or by your bed or anything like that? And creating more of an organized system? [applause]

Dr. del Castillo: I'm not aware of a specific drive out there. But there are efforts being made for individuals to make it uniform as possible. As I mentioned before, yes it is really a hindrance to have these things in your refrigerator, or taped to your gown, or whatever. I think that the most important thing you can do is to have your physician put it in

your permanent record, now that most institutions have electronic medical records. At least where I work, and I'm certain at Northwestern the same thing. They have an area where it says your desire. Whether it's a durable power, whether it's DNR, whatever it is. It appears in there because your physician writes an order to that effect. That's what you really need to make sure. Now, if you're out of town that's a different story. There should be a national... There's a lady back there who's waving madly.

Rosalie Guttman: I want to say that there is a federal living will registry based in Washington, D. C. And anybody can mail a copy of their advanced directives and it is recorded. And so if you go to a hospital or a facility and you have a note, a little card to say that you are registered with the living will registry, any physician or health care professional can call the number 24/7 and get your wishes. So such an entity does exist.

Ed: Ok did everybody hear? I will get that information and we will put it on the Hemlock of Illinois website.

[Speaker - question]: Does writing in the living will, saying that you don't want to experience any pain... Is the physician forced to follow that? I mean, you know, within reason.

Ed: There's a website of the movement's founder, Derek Humphry, at www.finalexit.org - not Final Exit Network. He's got for \$5 the single best living will document I've ever seen. And it's very, very specific where you enumerate your wishes, and what you do want and don't want. So I recommend that. It's www.finalexit.org ... It's all on our website Hemlock of Illinois, we've got links to it.

Loretta Downs: I have a couple of comments. Thank you very much, this has been fascinating. My name is Loretta Downs and I'm past president of the Chicago End of Life Care Coalition. And we're hospice advocates and advance care planning advocates. And I personally am a Physician-Assisted-Dying advocate. But 98% of the people who are in Oregon and use the law are in hospice care already. And here in Illinois, we have a form called POLST - Physician's Orders for Life Sustaining Treatment -

which is an amazingly empowering form for people who are reaching the end of their lives. It has a direction on tube feeding, DNR, and some other instructions. And it's a doctor's order. So filling that out would have saved you the trouble you had. This is new, a lot of doctors don't even know about it. POLST - it also started in Oregon. And I want to know, how do doctors die? [laughter]

Dr. Samo: Actually doctors don't die. [laughter] We're not allowed to. So that's all I have to say.

Dr. del Castillo: It depends, it's really a personal choice. There are some who hang on till the very end and have suffering. I've seen it. There are others who take the exit and they checkout. Look at ... I don't know this for a fact, it's an anecdote - the CEO of Coca-Cola, Roberto Goizueta. He was diagnosed with a terminal illness and died two weeks later. And this particular terminal illness - he could have lived at least two years. So the reality is that it's all in the individual. But as far as doctors are concerned, we're just like you - we just happen to take care of you.

[Speaker - question]: Is there a way of establishing what the policy of a hospital is? For example, Northwestern - what their policy is on Power of Attorney's? And whether there's a conflict between your doctor and a particular practice group and the hospital? I mean, what is that situation please? Thank you so much for coming. It's been wonderful. [applause]

Dr. Fintel: I can start and we may need to consult some of the attorneys here in the audience, but I am not aware that you can have more than one power of attorney. There cannot be conflicting, or the last one signed - it's like a will. The last document signed has precedence over the earlier ones.

[Speaker - question]: I'm sorry I meant one POA and how is it handled?

Dr. Fintel: Oh, one individual entrusted to be the power of attorney.

[Speaker - question]: If you have it, how can the hospital refuse it? And how do you know if they will or will not? What is their policy?

Dr. Fintel: Well I'm not aware we can refuse a decision about withdrawal of support. If that is... again, I don't know the legal issues, but if we're told support has to be withdrawn - I've been in that situation in the intensive care unit. And in someone who is terminal, we've withdrawn support and supported the patient during that process.

[Speaker - question]: I was addressing this gentleman's experience more than anything else.

Dr. Samo: Actually this brings up a very interesting point, about withdrawal of life support. All doctors, I think 95% of doctors in the polling felt that was a good thing to do in the appropriate circumstances. That has less safeguards around it than PAS. It's just, you know, the family says "Ok that's it. We don't want him to go any more. " And they just pull the plug. So really that's more of a form of euthanasia. And it has very few safeguards around it, very few questions about what the person may want. So it's an interesting dichotomy too. We need to talk about this more, don't we?

[Speaker - question]: The question is How did they justify in the Oregon law restricting it to people who are supposed to die within six months?

Ed: I think I'll try, I'll take that one. How did they justify restricting it to people who have less than six months to live? I think they were looking at... The Oregon law was passed, it was the first. It was one of the first in the world I think. And they were looking... you know there was concern, is there going to be a slippery slope? Will Oregon become a destination for "death tourists," etc. It was a decision for what was politically feasible.

And I think if I were going to advocate for the "Oregon law plus," the one change that I would make to the Oregon law is, I would say it has to be intolerable physical suffering, but not necessarily "terminal." Not intolerable mental suffering. There's a lot of discussion about, "oh you're suffering with horrible mental illness. You should be able to check out." I don't support that. It has to be physical suffering. But I think it should be intolerable physical suffering, regardless of whether you are "terminal." Because some of the saddest

and most difficult cases are people who fit that criterion.

[Speaker - question]: So what about Alheimers? That's critical. That was the one I wanted to ask. We have three very bright people here that if you have a clear advanced directive that doesn't survive dementia. If you knew for example that I signed an advanced directive, and I further had a dementia rider, a catch, so that if I am incapacitated mentally, I still want the advance directive to control the fact that I no longer want to live. But so often - and many people here have asked - you are suddenly, if you slip into dementia you're no longer competent to make a decision. What if you made the decision while you are competent?

Dr. Samo: Great question. [applause] But not a medical question. See, this is the question my wife kept telling me, "Why don't you doctors do something?" We've all experienced having someone we know or love spending years and years in disconnected dementia. I mean, near vegetative - not vegetative because they feed themselves or they can be fed. But sure, it's horrible. But it's not a medical question. This is what you're all here for. This is for you to talk - this is about laws. This is not about doctors. This is about what society wants, not what doctors want. So you know, yes I agree, but personally. But that's just personally. It's got nothing to do with medicine.

Ed: Let me try to give you my perspective on that one. My wife says to me that if she is diagnosed with early dementia, she wants to check out before she slips into a demented state. Lots and lots of people in the movement - especially the leadership of Final Exit Network - people who feel exactly the same way. I don't know how I would feel in that situation. Maybe I don't have too much experience with demented people... I know it can be terrible.

The key point here is: make sure your living will or your durable power of attorney specifies that if you're in that situation, you don't want measures to prolong your life.

Ok? If you're not mentally well enough to eat on your own, you do not want to be fed. That sort of thing. But the key point - the distinction here - is

that we are not advocating active euthanasia. We're not advocating something that says, let's say you become demented and a year or two have passed. It's clear that you're not going to recover. That the doctors should just give you a lethal dose of medication and in effect put you to sleep - what you would do with say a pet. We're not advocating that. We're not advocating active euthanasia in that situation.

Joan Sophie: Final Exit Network will work with people who have been diagnosed with dementia but who are still able to make their own decisions. To know what decision they're making and to act on it themselves. We will work with that person. So it's not once you've past the point where you cannot think about that and know what you're doing, then we can't help you. But if you do know what you're doing, contact Final Exit and we can work with you.

Ed: Let me repeat that. That is Joan Sophie who's one of our board members and she's an exit guide with Final Exit Network. This is one of the things that Final Exit Network does. If you are in early stages of Alheimers or other dementia, you're still mentally competent, you still know what you're doing, it's still clearly your act - they will work with you and advise your exit.

Dr. Fintel: Again let me address that issue as well from my perspective as a critical care physician. For many people with dementia, they don't die deaths due to cardiovascular disease, i.e. stroke or heart attack. Of course they may, but that may not be the reason for their death. Or from cancer because cardiovascular disease and cancer account for more than three quarters of all mortality in Western civilization.

But these patients - people, our family members - get infections because they cannot handle their urinary streams, they get urinary infections. They get pulmonary infections. Infections are a frequent cause of severe disability and sometimes mortality. We have to distinguish between, for example, offering basic care and antibiotics versus taking a very demented person into an intensive care unit, breathing for them when their pneumonia doesn't

allow them to and/or doing invasive procedures to diagnose the problem.

And that's what the durable power of attorney can be so helpful with - in specifying that, yes, if I become demented, I want standard, straightforward medical treatments (antibiotics and fluids and maybe short-term feeding), but I don't want to be in an intensive care unit with a breathing tube and/or a machine maintaining my existence. These are very difficult issues and they have to be worked out in advance with often a great deal of sophistication and with your physician to understand what can happen to your demented family members as they approach dying. So again, I personally am not here because I advocate any premature terminations or earlier termination of a demented individual's life who can still have basic medical management, but I strongly feel to avoid the intensive high-tech care that prolongs the life of someone who would have died naturally of that infection beyond the standard nutrition and antibiotics that we use for infections.

Ed: So if I'm demented, am I better off having my loved one request that if I get an infection having the antibiotic or am I better off having my loved one say no, no antibiotic?

Dr. Fintel: It's a personal choice.

Dr. del Castillo: Right.

Dr. Samo: I mean, it depends what your goal is. If you want to live longer get the antibiotics. I have a friend whose mother was severely demented. She got pneumonia. They called from wherever the mother was and said she has pneumonia, should we give her antibiotics? Sure, of course, of course. It was the biggest mistake I ever made in my life. Alright? So I mean personally, for me? If I'm demented? Give me nothing. Right? If I get infected and it's my time, it's my time. So... but that's my personal choice.

Dr. Fintel: And we disagree.

[Speaker - question]: Do all these things you're talking about - power of attorney and so forth - do they, as far as your experience, do they apply at

Catholic hospitals or is all that thrown out the window, if it's a Catholic hospital? [laughter]

Ed: Well again. . . Loretta Downs, past president of the Chicago End of Life Care Coalition.

Loretta Downs: It's a federal law that we all have the right to make these decisions and to legalize them in forms called power of attorney for health care and living wills. There could be disagreements but **the biggest disagreements that the doctors meet are the families that come in - and you may have done the documents, but you forgot to talk to them about what you wanted. And it's too late when you're in a crisis. Now, these are documents we need to prepare.** We need to have these conversations over dinner and prepare them when we're healthy. Because we get into crisis and you go to the hospital and you've never met this doctor before. He doesn't know who you are. In the case of the story of your mother, Dr. Fintel, your doctor, the one that you use knew her and could say easily to the hospice nurse, keep administering more morphine. And right now 70% of us say we want to die at home. And we're dying in hospitals and nursing homes. We're not dying at home.

[Speaker - question]: A related question. If you end up in a Catholic hospital, because if you call 911, you don't get a choice as to where you go. I wouldn't end up at Northwestern.

Loretta Downs: But you can transfer. That's true. I wouldn't want to go to a Catholic hospital.

[Speaker - question]: But if you end up at a Catholic hospital - and I'm sure a Catholic hospital is somewhat closer to me - there was no mention among the hospital staff or the people taking care of this particular person that there were any alternatives. It was one operation after another, and that final operation was going to require a permanent feeding tube inserted into the stomach. This was after three months in the hospital, the person not eating, they had a feeding tube, forced eating. And when the family said, how much further? We don't want to see you suffer, we don't

want more critical care. You know, this is not what our relative would want. And no, there was nothing in writing because this person was in their early sixties, I'm sorry to say. And eventually hospice was called. Someone knew of hospice and hospice became involved and the person got moved to hospice in Glenview. And then the person was allowed to die - with dignity. But it was a Catholic hospital the person was in. So my question is Do you have to make sure that you don't go to a Catholic hospital? Or another religious... She was 63...

Ed: Doctors? Do you know? [laughter] I don't know the answer. I'm not that familiar with many of the Catholic hospitals.

[Speaker - question]: May I ask a political question? Where the laws have been passed in Oregon and Washington, they're quite a different population, racially, religiously, than Illinois. What are the obstacles we face in Illinois to get it passed here?

Ed: Oregon has a tremendous progressive community. It's a mixed state; it's very similar to Illinois. You know, all the states have lots and lots of people who are aware and lots and lots of people who aren't. You know actually, I'm thinking of Mickey McIntyre who is the national program director of Compassion and Choices, and he thinks that Illinois is a near-next state in terms of getting a law passed. [applause] But folks, again I want to say sign up and contribute. Because in order for it to happen, we have to be a hell of a lot more organized than we are, we really do.

[Speaker - question]: What happened in Montana?

Ed: Montana was a decision of the state Supreme Court. In Hawaii they found a hundred year old law on the books, so we'll see. I think C&C is probably the national group that's closest to the strategizing, and they're not necessarily thinking that in all cases it will be that a law is passed. I think that's true. I mean, if you look at the problems we had getting marriage equality passed in Illinois. Maybe it won't be a law. I don't think any of us can predict what will happen in Illinois, other than that we've got to get organized so we can take advantage of this when we're ready.

[Speaker - question]: I'm a social worker and I had worked for a couple of years at a hospital that's mentioned. And I'm so glad that you had mentioned the fact that family is really what gets in the way at the end for everyone if they disagree. If they were unaware. If they're not ready to let go. No one's really going to fight the family at the hospital. It's not even appropriate to ask them to at those times. So it's good to discuss it with your family. And a lot has changed over the years. So one of the examples someone just gave about how they could end up in the hospital having one surgery after another, having a feeding tube, and it continues. That's not happening as often as it used to happen. I think Medicare had a lot to do with the change of that, and how they redefined subacute hospitals. So that's something to know that is changing. But it's really important to share it with the family. Because they are the ones sometimes that show up, and threaten the hospital and refuse to accept it. And that's really what will push it to continue.

[Speaker - question]: So with the three doctors on the panel, I'm going to ask a medical question. I think the main objection a lot of us talked about - minimizing suffering when there's no reasonable chance for recovery. A few years ago I filled out an advanced care directive, and I'm going to fill out a new one soon. The question for you is: there are a lot of questions there that I didn't know how to answer. I have two specific questions for the panel of doctors. There are certain things I knew would hasten my death, but I didn't know if they'd minimize suffering. So the two specific questions are one that's already been brought up, it was mentioned, refusing antibiotics. Clearly if you had a urinary infection, you would die quicker. Would that involve suffering or is that something that could be controlled?

The second thing is the issue of feeding. I've heard people say if they don't have a more aggressive, faster way to pass away, stop eating. Now to me personally, I've always thought starvation wouldn't be very pleasant. And I've thought, well what about the option of refusing food but not refusing hydration, which would have seemed to me maybe it might take longer but maybe be less unpleasant.

So the two specific questions are: is refusing antibiotics, does that lead to an uncomfortable death? And what about the option of refusing feeding but still having hydration?

Dr. del Castillo: Dying of an infection is a slow and not a pleasant way to go. I mean it takes some time. So in a person who is basically in a coma, let's say, and they have an infection. Or they have terminal Alzheimer's disease. That's the individual who actually will die of an infection - it may take some time. That's the individual who you don't treat. I think the individual who is somewhat viable, to not treat an infection is not a fun way to go.

Secondly, with regards to hydration. Yeah hydration will take you for a while, but starvation is also not a fun way to go, because your body starts breaking down and you will not - how should I say this - you will not... you will last longer that you really want to last, especially if you're being hydrated. So it would have to be both that you take away, not just one.

[Speaker - question]: In hospice care, is feeding compulsory? How do they treat an individual's need for nourishment if you're in hospice care? I thought that was the primary hospice situation.

Ed: I think the answer is no.

Dr. Fintel: I think it really depends on the decision between the caregiver and the designated person who's making healthcare decisions for that individual, or the individual if they're conscious enough. Feeding and nutrition is not mandatory in hospice. It's usually given but it's not mandatory.

Ed: One more, last question.

[Speaker - question]: I want to ask the doctors what to do when there is no advance directive and the family says we want to terminate life?

Ed: Ok, that was the second to last question.

Dr. del Castillo: Again it depends on the circumstance. I've encountered this a number of times where an individual shows up, they're pretty

much terminal in a way that... they have no vital signs or their vital signs are teetering on the brink, and there are many other factors contributing to the potential death of this individual - the imminent death. That's when you have a conversation with the family - if they happen to be there - or the physician, if you can reach the physician. And you make a decision over 10, 15, 20 minutes. And if the family says no, she would not have wanted it this way, or he would not have wanted it this way - you honor those wishes and you let go.

Dr. Fintel: The law does address these issues. I'm not an attorney but I understand the spouse - the surviving competent spouse - is in a position to make that determination if there's no durable power written or living will. Or a surviving child is I think next in order after a spouse or if a spouse is not available. So there are provisions for designated individuals to make choices. Now we all have dealt with situations in which the family is at brutal odds with one another. And those are very vexing for us as caregivers and for the family when there isn't unanimity. But we do certainly have recourse to what the law states, and I believe that the decision would go to the spouse and then the elder surviving child.

Ed: Ok last question.

[Speaker - question]: I was just going to briefly touch on the Catholic hospital situation. I personally was in that with my boyfriend six months before he died. And I had the durable power of attorney. And I had to call an ambulance to go to the closest hospital, which was a Catholic hospital. They were not very happy with my direction, as far as expressing his wishes. And I had to just insist, insist, insist as I called Superior Ambulance to transfer him to where his physicians were and understood. But it was just like going up the food chain and insisting and not giving up. Not taking their answer for an answer. And just, you know, being persistent. And also the fact that I had that durable power of attorney on me at all times. I was never without it for a moment. And it was very important... I was able to make it so they didn't put a tube down him, you know what I mean? I was able to stop what they were going to do. And then transferred him to the

hospital. So **I would just say, insist insist insist, and carry that power of attorney with you.**

Ed: Ok so I want to thank our doctors: Dr. Danny Samo. Dr. Jorge del Castillo. Dr. Dan Fintel.
[applause]

Please, again, contribute, join us. You can sponsor a house party. You can sponsor a speaking engagement. You can sponsor a showing of the film, How to Die in Oregon. The single biggest thing we have to do right now is enlarge the movement. So think about this, and talk to your doctors... So come talk to me and talk to our other board members. And we have all sorts of refreshments in the back, and Ken Leonard in particular will be very upset if any of them are left.

For more information and to join us:

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