

This session was also approved for 1 credit in the mandatory category of "hospice, palliative care and pain management", one of two special credits that physicians have to earn credit in within every two year re-licensing period.

## **Medicine Grand Rounds FY 2020**

### **“An Update on Act 39; Medical Aid in Dying in Vermont”**

**Presenters: Dr. Jaina Clough and Dr. Diana Barnard**

**Friday, February 28, 2020 – 6:45am to 7:45pm held in the Davis Auditorium**

**Dr. Diana Barnard:** Most of our robust data comes from Oregon where it has now been legal for a, maybe 21 years and from the very beginning they had well-funded, dedicated group of people, at Oregon Health Sciences Unit who are tracking information and they continue to be the most robust source of information, they publish an annual report and we can share the link for those of you who want to go look it up.

The other real game-changer is California. The population of California is very large so now that it's legal there the numbers of people asking about starting the process and using Medical Aid in Dying (MAID) is significant, there's about, around 400 people a year in California....um.... compared to our well 15....these are big numbers and it's really provided an opportunity to gain a lot more clinical experience.

I just came back last week from the first ever in the US National Medical Aid in Dying Conference and it was held in California and it was incredible. The group of people that came together to share experience and they really have really learned a whole lot by doing some really interesting clinical work at the bedside to try to gain more information about not only the process of asking and responding to suffering but also it's actually.... it is actually harder than you might think to help somebody to die – the body has an intense desire to live and so gaining more clinical experience about how we best help people achieve that outcome is important.

Of course, we have to pause and remember that hospice is the gold standard for the best possible end-of-life care and we can never say that enough or too early. It's the program that we have that provides interdisciplinary support for people that are experiencing multi-dimensional suffering....I use big words because this is internal medicine....(laughs) so it's just....we still....we have made some progress but we have a long way to go.

I am curious if anybody is brave enough to hazard a guess about what percentage of Medicare patients who died in Vermont were enrolled in hospice in 2013 when our law was passed?”

(Answers from the audience repeated by Barnard)

One respondent said “1%”

**Barnard:** I am hearing 1....10....

One respondent said “10”

One said “Less than 5”

**Barnard:** Less than 5? 24 percent, 24% (laughing) okay so maybe that sounds good to you but it doesn't to me (more laughing from the audience). So less than ¼ of people experiencing something we are all going to experience getting the best possible treatment for that experience. A little humbling.

Anybody want to hazard a guess about what that percentage was last year, 2019? 5 years after law was passed?”

Guesses from audience: 24%, 50%

**Barnard:** 42! 42! So I am not claiming that the law is responsible for that but I am saying that certainly the law has not had a negative effect on that and in fact perhaps our ability to have more open discussions about end of life care about what's coming and thinking about it.....is actually encouraging us to try to do a better job.

42% - is still less than half of those experiencing something we are all going to experience are not getting the highest standard of care for that experience. So we gotta keep workin'.

(Some moments to get slides up with some delay and talk of ditching slides altogether. Diana states “I sense the audience is losing faith....”)

Alright, so just a little more information out of Oregon – knowing that hospice is the gold standard.....just keep in mind that for individuals using MAID in Oregon and they publish a report every year, so we have an, each year an annual report and then cumulative data.

- 90% of patients were enrolled in hospice and that number is actually creeping up.
- 92% of people died at home. 5% in assisted living facilities, 1% in skilled nursing facilities.....there is another great statistic. 92% of people died at home. If you ask a random person on the street many, many people, not everybody, but many people want to die at home.
- There now are, last year there were 103 physicians who had prescribed under their death with dignity law. As you might imagine, in the early days there were a small number of physicians but that is continuing to grow as people gain comfort and experience under the law.....ah.....this is like a little nudge here.....from the beginning Oregon had really good academic support for their law and one of the things that I am dismayed about and still hoping to do is to get more support from our own institution – this is something that's legal in Vermont, its accessible to people, open to most of the people who are going to use this law, have answers, we are the state's largest answer center, we should have a more robust supportive program to help providers and to help patients navigate this law. Okay, off my soapbox.

Um....and just a little update. Oregon just put a little tweak in their law, which said that....passed at the end of last year is effective as of January....that if a physician who receives a request from a patient for MAID and that person at that visit is determined to have a life expectancy of less than 15 days then they do not have to go through the waiting periods. They are eligible right away....all the steps still have to be done....and we'll talk about those in a second...but they don't have to go through the waiting period and for those of you that might worry about that I'll just remind you that the data is really showing that patients, no surprise, most of our patients want to live and they want to live as long as possible and they also are very worried about how they are going to die. All too often a request about MAID may be thought to be made too early but more often it is made too late and people that have genuinely had an interest in the process are asking at a time when it is not possible, so this was an attempt on Oregon's part to make sure they are meeting the needs of patients who are vulnerable, who are dying and who want access to a legal process.

So....um...alright, who want to just give a shout-out? Why do you think people ask about MAID?

(Barnard repeats audience answers in order of the shout-outs):

- Fear
- Don't want to be a burden on their families
- Control
- Pain
- Inadequate access to good end-of-life care
- Prior death experience that didn't go well....most of know plenty of people with that right?
- Depression
- Wanting to pick the time

So again, we can turn back to Oregon, our friends in Oregon, for data around this (shows chart) this is a snapshot from a chart just looking at it, the first column is 2018 and the second column is the total since inception of the law, so 20 years of experience so....the biggest reasons that people are asking about this?

- Losing autonomy...another word perhaps for control.
- Less able to engage in the activities that make life enjoyable.
- Loss of dignity.
- Losing control of bodily functions – that is just such a ..... I think we all know patients who are struggling to be able to take care of their own personal needs at the end of their life is just....it's for many people a tipping point....and in case I forget to say so later, this does not mean to imply that anybody who is born with or who is living with a disability that might require assistance and help and has a full life to live can adjust to those kind of changes – but people at the end of their life have a much tougher time with it....

.....em.....other things.

- A burden on family, friends and caregivers.

So you see the numbers and percentages – so autonomy 92% – pretty high – 90% activities – you get down into the 60’s when they talk about dignity, bodily functions – notice inadequate pain control of fear or it is lower than some people might suspect but not zero, 25%. And financial implications....really small.

So....can you go back for a second....I just might also add that just to emphasize the information from earlier, remembering that most of these patients are on hospice – 90% - more than 90% of these patients are getting hospice care which we believe to be the gold standard – it also happens that most people who utilize the law are white – are educated beyond high school and...are financially stable and have insurance.....in early days of passing the law there was concern that...about coercion or that individuals with limited resources or lack of psycho-social support might be more likely or coerced into using the law. The opposite is true – at the same time I think we are learning that we may actually have some social justice and access issues. Are we actually offering...and making sure that this legal option is available to individuals across our spectrum of socio-economic status, race, economics, whatever. That’s becoming the really new hot topic.

So in Vermont, it was a grassroots effort that took a lot of years – 12 to be exact – lots of education, you know, lots of public hearings – I traveled all around the state to talk to people, to talk to the providers about why I thought it was a reasonable thing to add to our tool box.....I went to the legislature more times than I can count.....as a physician to testify.....along the way our legislators, because they’re thoughtful and I really appreciate how you know at the State House, we the citizens of Vermont, really trying to do right by us, they are very thoughtful, but they often don’t hold a lot of education or information about a specific topic, but they’re interested.....so ah... they were given a lot of information. They had significant concerns about the lack of education and awareness about other aspects of really good end-of-life care, hospice care, palliative care for those earlier in their illness and so we responded to that and along the way to passage of Act 39, other bills were passed that.....don’t let you bow and arrows....but you know that mandatory CME we now have? (laughs) And the mandatory CME in pain management and palliative and hospice medicine? So ahh,....just to say that along the way to passing this bill we were responding and listening to other concerns.....it’s a topic for another day but some of you also know that along the way my own professional journey transitioned from being a Family Practice doc to specializing in the care of those people in this population – so it’s been a really interesting life journey.

...ah...it became legal in May of 2013, we call it Act 39, professionally refer to it as MAID, and on the Department of Health website the official bill is also called Patient Choice and Control at the End of Life.....just so you know if you are looking for it.....at the End of Life.

**Dr. Jaina Clough** begins here: And so, since the law passed the Department of Health has been collecting and reporting utilization data and in 2015 there was an amendment....Act 27....passed that specified the need for mandated biennial annual reports. We've had 2 so far...January of 2018 and January of 2020...reporting on utilization and the data collected is how many patients have met the requirements of the act, the underlying causes of death and the number of prescriptions that have been filled by qualified patients. So the data is collected from the physician reporting form. There are handouts at the back of the room. I don't know if anybody had a chance to pick them up but the top page of that handout is the physician reporting form which is available on the Department of Health website and is basically an excellent guide to all the information you need about Act 39 and is the source of much of the data we are collecting.....there's also a form that's been in use since 2015 called the follow-up form and that's a form that the prescribing physician fills out within 10 days of a qualified patients death – basically reporting on how the person died, if they took the medication, took the lethal dose of medication, and the state is also accessing the Vermont Prescription Monitoring System...for information about prescriptions filled. And so since 2013, through June, 2019, which is the end of the data collection period there have been 87 events which, events means the people who have completed the Department of Health paperwork and met all the requirements of the law. The majority of those patients had cancer and 13% had ALS, and the rest of the cases were a mix of conditions but primarily neuro-degenerative conditions, like Parkinson's disease, multiple-system atrophy, etc.

So, 57 people died by taking the lethal dose of medication, so that is about 66% of people who have actually gone through the whole process of approval. And 25% died of the underlying cause of illness and the rest are basically other causes of death – and also there's a discrepancy that is presumably of the people who have gone through the process but are still living.

And I just want to call your attention to this article published by our faculty, Dr, Kara Landry, Dr. Alyssa Thomas and Janet Ely from our oncology department (a bit of mumbling, Diana says, “who snuck in.”). So, and Janet, I welcome any contributions obviously from you as you are the actual author of the study. This is a survey of physicians affiliated with UVM Medical Center looking at experience and attitudes regarding MAID.

And there were 81 surveys returned.

52% of the respondents were in primary care, 23% were in neurology and 16% were in oncology.

And what the surveys revealed were that the overwhelming majority of Vermont physicians surveyed in this group support Act 39.

50% Strongly support

25% Somewhat support, and there were 20% who had some level of objection.

And that there is a definite need and desire for more education regarding patient counseling and also the whole process and the paperwork needed.

And that less than 50% of providers felt they have the information they needed.

Future directions include implementing an educational opportunity for Vermont physician to improve their knowledge of Act 39. Here we are! One step. Anything to add, Janet?

Alright.

And the survey also collected information based on the report and recall of physicians about patient's motivations for pursuing the MAID and what we are seeing is that it really mirrors the reporting from Oregon in terms of autonomy being the most important motivating factor. Loss of autonomy.

So now, I think Diana and I have both struggled for years to figure out how to kinda review the law itself and the sort of all the information that goes with the law, how to review it quickly. So we're going to do a pop-quiz. The good news is that it is open book. If you picked up a form, the physician reporting form has everything you need to know on it. So the first thing we are going to talk about – I'm going to quiz you and just give a shout out – um –

- Who is eligible for MAID in Vermont? What are the characteristics of eligibility? A person must have a.....?

Answer: terminal illness.

Yes. What else?

Over the age of 18.

Yes.

Capacity.

Yes – decision making capacity, obviously the most fundamental element of eligibility. That can change so one of the most important things about being a physician involved in this process is being able to sort of track and acknowledge when decision making capacity changes because as we know, as serious illness progresses, it often impacts capacity.

What else?

Vermont resident. Exactly. So the residency determination is left up to the physician (laughs) but the general guidelines are the State Department of Health has a FQA section which is quite useful and what it describes is criteria for residency are having paid taxes in Vermont or owning

property....those are the two sort of.....am I missing anything? Response from audience, maybe Dr. Barnard) “driver’s license.”

Drivers license....yes, so, good job.

So terminally ill, capable adults oh and able to self-administer (laughs) that is most important....so that again is also the physician determination, and just being able to assess the functionality of the person to self-administer the medication so this is how we can insure that this is actually the person’s own, an act of their own free will.

And so the law doesn’t specify what modality a person would use to self-administer....most commonly that’s oral so drinking the medication in 4 to 6 ounces of liquid and it tends to be in slurry form – so if people do have challenges with swallowing that can be a real concern if they are going to be successful in self-administering. Self-administration can also be accomplished by a G-tube, so if the person can use a syringe to deliver the medication to themselves through the G-Tube that is also considered self-administration. And Diana has some more information about other regions of the country that have explored using rectal self-administration. I am gonna leave that to her.

And then obviously part of the eligibility process is that the person has actually verbalized the request and made their wishes known.

Let’s talk about the next step which is the all the sort of the time line of the steps of the process. So, I am going to lead you into this part of the quiz. So a patient must make two verbal in person requests of their prescribing physician separated by no less than? How many days?

Answer: 15.

15, yes. So, 15 days. So that is the sort of standard waiting period to insure that this isn’t like an impulsive or sort of rash request.

**Barnard** pipes in:

Might I just add in terms of counting of the 15 days for my oncology friends, I am no an oncologist, but I know that sometimes the way we count in chemotherapy that the first time something happens is day one. I just want to clarify for everybody that in this case 15 days is meant to be more than two weeks. So if you make a first request on a Tuesday, the second request cannot be any sooner than two weeks later on Wednesday – so two full weeks must have passed.”

**Clough:** Great. And then there are two other pieces of paper that people need.

Audience question? Any thoughts?

The written request, yes. So the written request is basically a statement that the patient signs that says that they are making this request of their own free will and they’ve been informed of their diagnosis, prognosis and all options to treat their condition and palliate and it has to be signed by two people who are neither family nor health care staff so people often use friends, they can use

notaries, through our hospice program they can use hospice volunteers. And the idea is that the person is not an interested party or has any sort of special interest in this action.

And then the other piece of paper is the secondary consulting physician so this is getting a second opinion, kind of all of the above, capacity, diagnosis, prognosis, and the fact that this is the persons wish. And then, after either the second visit or the written request....those are the sort of last....considered the last two steps....there is an additional 48 hours final waiting period and then the prescription can be written and coordinated with the pharmacy. And then finally, the physician must inform, I'll spare you the quiz part, but the physician is obligated to inform the patients of their diagnosis, their prognosis, all their treatment options – and the physician is obligated to explore all options to palliate their symptoms and sort of address suffering. It is again this is to insure, is written into the law to insure that we are not seeking any short cuts to really provide the best quality end of life care.

And then another fundamental part of this whole process is that the physician must remind the patient of their right to rescind the request. So, I personally spend a lot of time on this because unlike any other prescription we write there's no, there's no implied recommendation that this is what you should do, this is entirely the person's wish.

People can change their mind at any time and it is just so important to remind ourselves and to remind people that there's just never an obligation to move any further forward with this process if they do not feel ready. And then of course, as with all informed decisions, really making sure people really understand the consequences of this action and the risks, which we'll cover a little bit later, and the expected outcomes.

(Question from the audience: I just have a question about the secondary opinion? Is that someone that just reviews the chart or does the patient have to see them face to face?)

Answer: So the law doesn't actually....the form doesn't specify if there has been a visit, however, in practice the secondary physician typically has had contact with the patient and is able to confirm decision making capacity and patient understanding of the decision....and patient understanding of their illness and prognosis.....so it is typically that somehow they have been involved, it is not just based on chart review. But the form itself doesn't actually specify a visit date. So...

**Barnard:** I think the implication is that there will definitely have been a visit – the date is not mandatorily part of that 15-day period - but put it this way it could be before or potentially be just after....so just bearing that in mind.

**Clough:** So, the other piece of this that is so important is, we talked a lot about ambivalence but I think that the physician sort of concern about impaired judgement or decision making capacity and if either physician involved has any doubt than obviously you would stop the process and communicate to the patient that you feel that this isn't an appropriate thing to continue. And I think this is kind of....for me, in some circumstances where people are kind of, are losing their decision making capacity and it can be very difficult to kind of make that call in the middle of the process, but if there's any doubt, stop the process and certainly....the question.....someone had



mentioned depression and this is a really frequent question like how do you discern a depression that's so severe that it is actually interfering with decision making capacity and that can be a difficult discernment especially because with people serious illness are often grieving their losses and experiencing a normal adjustment to the dying process. So if there's doubt it is just always advised to seek a second opinion or seek a psychiatric evaluation or a therapy evaluation. So thinking back to how we started which is thinking about being in the position of receiving requests from patients....just some thoughts that we have....just track your own response including ambivalence...and no one is obligated to prescribe....and to consider the request for MAID as an opportunity to explore concerns about dying and about suffering. And then actually taking a practical role.....depends on a lot of variables....it may depends on the relationship you have with the patient....it may depend on your personal beliefs and always we encourage you to use your team. Obviously people receive these requests from patients when they are not in a position to prescribe, so if you are a social worker or a PA or an NP...you may be fielding a lot of these requests but it is not necessarily your direct responsibility to kind of practically address the request and so recruiting you're....whatever interdisciplinary team you have access to and obviously your hospice team can be quite useful.

So we are going to do a little demonstration. Of a request. We are going to meet Donna – Donna is a 50-year old mother of two young adult daughters, and she was diagnosed with stage one endometrial cancer two years ago and she experienced a recurrence six months ago with a mass in her pelvis and a mass to her right asa tagma. She underwent six cycles of carbo platinum taxol, discontinued chemotherapy due to the fatigue and side effects. And she's had some right hip pain but it has been managed with Tylenol and she is fully functional and she is feeling a little better off treatment and she is at her primary care office for a blood pressure check and a flu shot. And apologies to any oncologists in the audience, this is not the most refined oncology history but the purpose is we're just going to show you a couple of the responses to a request for MAID and the goal here is not to show a whole sort of palliative care conversation or even a conversation about goals of care but just to kind of show you....to isolate out the request. And I would just encourage you not to be worried about eligibility or anything about the law itself...we're just going to just to sort of isolate the request.

So this is take one:

**Clough:** I am the primary care doctor.

Donna, good to see you. Hi. Blood pressure looks good and I know that you already got your flu shot. So, just curious, how are you feeling since stopping the treatments?

**Donna: (played by Barnard):** Ah, I feel so much better. My blood pressure is down and my energy is better it's just....yeah, it just, um it's good.

**Clough:** Good, sounds like it has been a good decision for you. Is there anything else on your mind today?

**Donna:** You know, one thing is...you know during the day I seem to be fine I feel like I've been getting out...my husband and I are doing some things, gardening .....but at night...my mind is going around and around about the end and I want to talk about the law because I'm worried how it's going to go and I want to go on my own terms.

**Clough:** Yeah, um Donna, yeah that is, that's important. I should tell you that I don't have a lot of experience with the law, and you know I think in the big picture you're doing really well right now and it's kind of early to think about that – so, why don't we just touch base about that at the next visit?

**Clough:** Alright. That was take one. (audience is responding with a bit of laughing)

That was take one. This is take two.

**Clough:** Donna, good to see you.

**Donna:** Good to see you too. I can't tell you that I am too happy about being back in the doctor's office.

**Clough:** I can imagine.

**Donna:** But my blood test was so much better!

**Clough:** Yeah, it looks great today, you've got your flu shot....I am really curious, how are you feeling since taking a break with your chemotherapy treatments?

**Donna:** You know, thank you for helping me make that decision. I've been so much better, I've been able to do things I haven't done in months, not having to schedule my life around those damn visits and I been getting out with my husband and ....it's been good for me.

**Clough:** I am so glad to hear that. Is there anything else on your mind today?

**Donna:** Honestly, one thing I wanted to talk to you about is my sleep....I mean, during the days things are going great and every day I wake up with the energy to do the things I want to do but at night my mind is on a constant loop thinking about the end because I know it's going to come someday and I'm really worried how it's going to go and I want to have the law so that if things get tough I can end it on my terms...

**Clough:** Yeah, tell me a little bit about what you know about the law?

**Donna:** Well, I know that Vermont has a law that allows me the right to make a decision about when to end my life when I'm close and when I am suffering.

**Clough:** Yeah...Vermont does have a law that allows a person to take a medicine to end their life when they have a terminal illness and I really appreciate that you could bring this up with me, I appreciate that you are comfortable bringing up this question and I wonder if I could ask you a few more questions about what this means for you....would that be okay?

**Clough:** I guess my biggest question is, well, I am just curious, curious about why this option is important to you?

**Donna:** Well, I mean, I just can't see myself laying in the bed and having an accident, having to have someone wipe my butt... I mean, you know, I grew up on a farm, I've spent my whole life doing...being self-resistant, reliant, taking care of myself.... I just can't imagine putting anybody in my family through that.

**Clough:** Yeah, it sounds like you are so aware of who you are and your independence and the idea that this could be hard for your family is painful.

**Donna:** Yeah, and you know, I watched my father die and it was, it was terrible...it was terrible and my mother had, she had such a different experience so I know it can be different and I think my Dad died horribly because there was no information and he didn't know what was happening, he was a victim. My mom was allowed to take control and in that way I am a little like my mom.....I want to have a plan....

**Clough:** May I ask you what you are most worried about?

**Donna:** That I will linger in bed with my eyes open and no meaningful life...

**Clough:** Thank you. So you have shared a lot of information about what worries you and what and how you envision dying.....we'll talk more about that....and that's take two.

So, any thoughts?

Did the first one seem realistic or was it a little bit too much?

**Clough:** Well especially for primary care, you're like, the patient's doing well, its a bit of a direction change...and, any thoughts about the second one?

What's that?

Audience response: “Empowering.” “We got a lot of information...”

**Clough:** Thank you, yes.

We have about two minutes.

**Clough:** Yes, so I think we just wanted to demonstrate how also these requests they don't have to be the thing itself but about the why the person's asking – and nothing about eligibility, nothing about my feelings about the law or the process.

Question from Tim Lahey (Chair of Ethics Department). Yes.

**Tim Lahey:** To that point I would say that what you talked about should/could be ethically mandated whether you support the law or not. You should explore those things, whatever you believe shouldn't matter.

**Clough:** Thank you so much...yes, I like that....ethically mandated! Yes, it is helpful to kind of dissect out the parts of this and to know that this part is really a universal way of responding to patients and their concerns....in a way Act 39 itself can be a big distraction and in part because if we're uncomfortable, or uncomfortable with the process and it just creates again our own ambivalence....but this part we want to be available to everyone.

Thank you. Thank you, co-actress.

**Barnard:** Um....Eric Cassell, way back in 1982 but one of the greatest quotes I think I have seen....so let's just take a moment to read it.... “suffering is experienced by persons, not merely bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity.” So just you know just keep that in mind....it is not just about pain, shortness of breath, this is about who somebody is. Forgive me, I love cartoons - “I'm the one with the medical degree – I'll determine whether your back is bothering you or not.”

Just a reminder, you know this is not about us, this is about the experience of our patients and I know that most of us remember that most of the time but so um ah.....

So. Ah. Right. When you're responding...I think that's okay we can stop there....the most important things that we hopefully just demonstrated is, be open minded....be curious, listen... these are some examples of phrases that you might use...this is not meant to be a recipe...you are not going to just write these down and use these with your patients – you have rapport with your patients, you know what comes to mind, but these are just some ideas to stimulate the right kind of questions.

What does suffering mean to you?

What are you most hoping for? What are you most worried about?

Really important questions.

What does being a burden look like to you?

Different for everybody. Right? As we know some people are very comfortable being cared for potentially being in bed or being a wheel chair rider while being cared for. Other people see that as a total burden. If we could change, right, that this is the concept of the biggest worry ...if we could change that or make that go away...would it take away this as an option?

This is a really powerful one.

How would you know it's the right time?

I just asked this question of someone this week and they said...ah that is a really good question...and really just, just spondered more thought and more exploration of this question, this is what this is all about.

**Clough:** I stole this question from a colleague, it was an oncologist colleague nursing a 20-year old man and this was like in the early... in the first year of the law....this question just came forth and it was such a human question and this 20 year old man said, "when I can't get up and walk to the bathroom, that is when I am going to want out." And he, that is exactly what his experience was....is that he reached that place....he didn't end up utilizing Act 39, but in the time....I use this question a lot as a really great barometer because some people would say 'I'd do it right now if I had the medication'...and other people say, 'I don't know I'm not sure how I'll know' which is also normal....so I think it just it gives you a sense of where people are at in the relationship to this action.

**Barnard:** Ah, this is another really important concept, right being gentle with your information and using patient-centered language to share - be honest and realistic specifically about what you will do. Do not say, "Hospice will take care of everything and you won't suffer at all." You know that is not fair, that is not realistic. We need to use language "this chemotherapy is going to work for at least a few more months"...whatever it is that we say patients deserve to hear it in a way that really is not overpromising and only focusing on the positives - but focusing on the range and the support that we're going to offer throughout the process. And always remembering along the way to explore and respond to emotion when you're in a conversation with a patient and there is a strong emotion, that emotion must be attended to before any conversation can move forward with the silence? with a validating statement?

“I can see that you are feeling overwhelmed...let’s take a moment.” Just remember we get so busy in our list of questions and responding we sometimes forget to just look at our patient and think “what’s happening with them right now?”

Always important to remember along the way as providing excellent end of life care that we always want to be talking about other options that your patient has to minimize suffering. Have you discussed what might happen when they are close to the end of their life and their code status, in a reasonable, patient-centered way – normalize options to stop burdensome treatments that may prolong suffering – you know this question of, “is what we are doing now helping you live well or are we moving toward or might we get to a place where those very treatments are actually prolonging your suffering? Whether that’s artificial nutrition or chemotherapy or use of frequent antibiotics or anything else...we really need to be reminding ourselves that there’s a lot of other things that we can remind our patients about that give them a sense of control that address some of these worries.

And considering alternatives for those who that are interested in hastening their deaths but may not, for various reasons qualify for MAID, thinking about other options like voluntarily stopping eating and drinking which is a whole ‘nother discussion.

Do we have time for questions?

Just quickly, and feel free to ask questions if you want.

I am very cautious about this information and there’s a reason you can’t just type this into the internet so please be careful with the information but just to let people know because you are internal medicine docs and you’re curious, all the drug protocols require a lot of preparation in terms of stopping certain medicines and changing your diet. They definitely require treatment with antiemetic’s to make sure medications don’t come back up.

In the early days we were using rapidly acting barbiturates which were lovely! Secobarbital, Pentobarbital, very quick acting...put you into a coma, cause respiratory depression and death – peacefully and very quickly. Those medications are no longer available in the United States due to terrible things like the medicine being used for executions. Later on a protocol was developed called DDMP2 a combination of dig (digoxin), diazepam, morphine and propranolol, so you are seeing a combination of medications sort of designed to effect different parts of our body that are keeping us awake – designed to help you go to sleep, be in a coma and then end your life through respiratory depression or cardiac death.

The latest protocol which I was just exploring when I was out in California is switching out now...putting in amitriptyline in for propranolol.

Just very quickly, these guys in California have attended like more than 200 deaths – they are enrolling people in their study – they are using these small O2 sat (saturation) monitors, very small EKG machines that are not burdensome, working with patients and seeing what happens as people die and it turns out, not surprisingly, that the heart can tolerate pericardia very, very well for a long period of time – it also seems to be true that it did just probably in some ways getting mixed up and lost in all those other medications. So there's now a recommendation to switch to amitriptyline which sadly a lot of us know from our primary care experience causes tachycardia and arrhythmias which the heart does not tolerate as well. And also for people that are high risk or maybe more at risk for having prolonged dying you can separate out the ditch you use your premedication, 30 minutes later give the digoxin so it has time to be absorbed and then later give the rest of the cocktail. So the most important thing is that the bottom line is: that these are still evolving, this is a growing science. If you are going to participate even this week, if you get to a point where you are getting close to working with a patient, please reach out to the local experts – the pharmacist that we use is Rutland Pharmacy, Smilin' Steve he's a wonderful guy – you can call him Jaina, I, your local hospice medical director please reach out because (there is laughter over the name Smilin' Steve). That's his name! Smilin' Steve, his chosen name.....look at his ads.....he is funny.....he is very patient-centered.....

**Barnard questions audience:** Alright, what's this? Who knows what this is? How many nurses are in the audience? It is actually a Foley catheter.

This is a rectal catheter which turns out to be very useful for rectal administration of the medication so you see here this is poked up...you can put it in and inflate the balloon above the sphincter and you can administer the medications this way. One of the things that's becoming clear is that the medications go into the stomach have to leave the stomach but they get absorbed in the first part of the small intestine. It's been a long time since I've done anatomy but I saw fascinating anatomy slides with all of the little rugae and the things that are responsible for absorbing stuff, food, medication...turns out in a lot of illnesses, any kind of cancer, with cachexia, especially gastric cancer, pancreatic cancer, there are many states that effect those ruage and make it very hard to absorb the medication and the biggest concern about the use of this protocol is there are some other small issues like obviously you could regurgitate, you know, not be able to take it all those would be big ones – but the most common one is a more prolonged dying. I think most of us know that when someone is hoping to hasten their death and we have someone from the medical team in attendance to offer support, generally a member of the hospice team, we're really hoping to have it happen within an hour or two....with the secanol and pentobarbital like a half an hour...but an hour or two is reasonable....longer than that and you start to get stress, understandably... “how long is this taking,” “what if the patient wakes up?” ...which is extremely unlikely but some of these deaths can take many hours especially if you have a higher risk patient where they have red flags which we have a slide on and so for some of those patients using the rectal route is a way to

bypass the changes in the upper GI tract which have not happened down below so this is sort of interesting – I have not used this yet.

**Clough:** I think we can, why don't we just leave that – because I think we'll just cover that sort of concept of prolonged dying becomes a complication in part – because we are learning how to create sort of realistic expectations on the part of patients and families and because the drug protocols are changing – and this is still such uncertain territory – we're all trying to evolve and adapt and create appropriate expectations but I would say that that complication of... whether it's difficulty ingesting and getting the complete dose because of dysphagia or the body not responding to the dose the way that we would anticipate because of cachexia or because they have ALS but their heart and lungs are very strong and may not be impacted by the doses, the experience of it kinda not going as planned is really the complication that causes the greatest stress for people. And the complication rate in general like technically difficulty ingesting or even regurgitating the medication is less than 5% looking at the Oregon data. Attached to that physician reporting form is an instruction sheet that was originally written for Seconal which has been blacked out, but that is also just a general guide to try to create a process for families to understand about how to move through this or a patient instruction sheet and I think we have to stop but we are going to stay afterward to answer questions. I don't know if we have time for a couple of questions right now?

End of recording.