

2016
HOT ISSUES
IN HEALTH CARE

colorado health
INSTITUTE

#HIHC16

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End-of-Life Options in Colorado

The Delicate Task of Implementing Proposition 106

Panelist: Daniel Handel, M.D. Denver Health Palliative Care
Panelist: Megan Schrader *The Denver Post* Editorial Board
Panelist: Kat West, J.D. Compassion & Choices
Moderator: Alex Caldwell Colorado Health Institute

Welcome! I am pleased you have chosen to join us for this very important and timely discussion on one of Colorado's newest laws on the books – the End-of-Life Options Act, which was once Proposition 106 and has been approved overwhelmingly by voters just a couple weeks ago. Now the question is what's next?

Introductions

Moderator

- **Alex Caldwell**, Policy Analyst, Colorado Health Institute

Panelists

- **Dan Handel**, M.D., Chief of Division, Denver Health Palliative Care
- **Megan Schrader**, Editorial Writer, *Denver Post* Editorial Board
- **Kat West**, J.D., National Director of Policy & Programs, Compassion & Choices

My name is Alex Caldwell and I am a policy analyst at the Colorado Health Institute.

By a show of hands how many people have been to a previous Hot Issues in Health Care Conference? How many have been to more than one? More than 3? (Alex awards raffle tickets)

So we have some Hot Issues veterans in the room. You may not recognize me as well as the other members of the CHI team because I'm one of the newest – I joined in August. I come to CHI with more than six years of experience in both health and education, focusing primarily in measurement and evaluation. I earned my Masters in Public Health in health policy at Columbia University in New York and most recently have come from Geneva, Switzerland, where I was doing performance measurement in global health.

I'd like to introduce my panelists and then run through the plan for our session today. I am pleased to be joined by:

- **Dr. Dan Handel.** Dan is the founding Chief of Palliative Medicine at Denver Health since 2013. He previously held senior clinical staff appointments at the National

Institutes of Health for a dozen years – there he founded and directed one of the first accredited fellowship training programs in Palliative and Hospice Medicine. He has presented internationally and written extensively on his craft – we are pleased to bring his perspective on this issue.

- **Megan Schrader.** Megan is a columnist and editorial writer for The Denver Post. She has covered local and state politics for newspapers in Missouri, Florida and Oklahoma. She covered politics for The Gazette in Colorado Springs for four years before joining the Post in September 2016.
- **Kat West.** Kat is the National Director of Policy & Programs at Compassion & Choices – this is the largest organization in the US to be advocating for medical end-of-life options for patients. Kat is trained as an attorney and is an expert on medical aid-in-dying policy and implementation. She brings more than 18 years of program development and management experience in government and nonprofits. And importantly, Kat is responsible for the Access Campaigns to implement medical aid-in-dying in authorized states including Oregon and California.

We are grateful to have all three of these experts with us today – before we hear from them I want to do a bit of level setting.



Three Takeaways

- 1 What we know about Colorado's End of Life Options Act.
- 2 What we don't know about how it will impact provider training, patient communications and vulnerable populations.
- 3 What can we learn from other states.

There are three things I want you to take away from today's session.

First, is what we know about Colorado's End of Life Options Act.

Second is what we don't know. I'll share some questions that people have raised in thinking about what this law will mean for Colorado, including how it will impact provider training, patient communication and vulnerable populations.

And last is what we can learn from the experience of other states implementing medical aid in dying laws.

Plan for the Hour

1. Medical Aid in Dying in Colorado
2. Experts Weigh In
3. Your Turn – What's Next?

We have an hour together. To get to those three main takeaways, we'll do three things:

- I'll introduce the law to talk about what it does tell us, what it does not tell us (the questions it raises), and what other states might tell us as we begin implementation.
- Our three expert panelists will start to answer these new questions and give their perspective on, "what's next?"
- Our experts will join you in a conversation at your tables about what's next for your own stakeholders.

Since we have this time allotted for questions to our panelists and then discussion with them at your tables, I'd like you to hold onto your questions comments until those times – but jot them down because we're looking forward to hearing from you.

Plan for the Hour

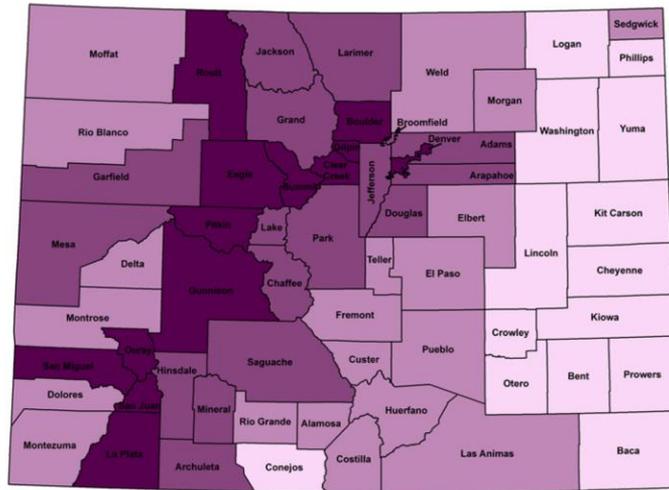
1. Medical Aid in Dying in Colorado
2. Experts Weigh In
3. Your Turn – What's Next?

I'll start us off.

Medical Aid in Dying in Colorado was authorized via ballot measure just a couple weeks ago. And it passed, by a lot. In fact it was the biggest win of the night in Colorado.

AUDIENCE PARTICIPATION: Does anyone want to take a guess as to what portion of Coloradan voters approved the measure? (Alex awards raffle tickets)

Proposition 106: The End-of-Life Options Act



Voters approved the law by a two-to-one margin. That’s a big win. It’s particularly big when you think about how emotional much of this campaign was. There are many issues on both sides of the aisle on this act, and as we move forward, some people and institutions will continue to raise those questions. So they’re still relevant and we’ll address some today.

Raise your hand if you’re joining us from the Eastern Plains. What were you hearing during the campaign, and was this result surprising? CHI will continue to monitor how this law is implemented. We’ll be looking at this region to see what happens with physician uptake. Think about what other questions you might have us investigate.

So we have to ask – what’s next? The law is on the books – what do we know about it, and what does it mean for health care in Colorado?

The End-of-Life Options Act: Nuts and Bolts

- Colorado's End of Life Options Act **authorizes the prescription of aid-in-dying medication** to a qualified individual.
- They **may choose to self-administer** the drug to bring about a peaceful death.



First thing – what do we know about this law?

Colorado's End of Life Options Act authorizes the prescription of aid-in-dying medication to a qualified individual. They may choose to self-administer the drug to bring about a peaceful death.

The “self-administer” part is important -- it has implications for eligibility, and it's important because it distinguishes this law from euthanasia, which would involve active physician intervention to cause death.

The End-of-Life Options Act: Nuts and Bolts

Who is Eligible



- Adult (18+) Coloradans
- Terminally ill
- Mentally capable

First thing – what do we know about this law?

- Who is eligible:
 - **Adult:** Patient must be a Colorado legal resident aged 18 or older.
 - **Terminally ill:** The patient must have a diagnosis of a terminal illness and a prognosis of six months or less to live. The patient must consult two physicians who agree on eligibility. Importantly, neither age nor disability constitutes a basis for qualifying for the law.
 - **Mentally capable:** Patient must be able to make and communicate an informed decision to health care providers.
 - Eligibility hinges on whether someone is capable of informed decision-making. So people that are mentally incapable due to dementia or Alzheimer's are ineligible.

The End-of-Life Options Act: Nuts and Bolts

Doctors are protected

- Doctor is **not liable** if all steps are followed.
- It's **voluntary**.
- **Patient may choose not to take prescription** at any time.

Good to know

- **No abuse reported**.
- Cause of death is recorded as underlying illness, **not suicide**.
- Law is in effect **January 2017**.
- CDPHE is tasked with compliance and **annual reporting**

First thing – what do we know about this law?

Protections

- This is essentially an immunity bill. Physicians are protected and are not liable for civil and criminal litigation and are protected from penalties like discipline or loss of license. Physicians are responsible for following protocol and documentation.
- It's voluntary. A facility can't force an MD to prescribe. A facility can prohibit a staffed/contracted MD from prescribing – they must notify both patients and doctors in writing.
- Patient may choose not to take prescription at any time

Good to know:

- Proponents say that in any states using medical aid in dying over the past 19 years, there has been zero cases of abuse.
- Cause of death is recorded as underlying illness – not suicide.
- Law is in effect in early January 2017.
- CDPHE is tasked with compliance and annual reporting

Medical Aid in Dying in Colorado: What's Next?

Questions remain

- How should provider **training** change?
- How are these options **communicated**?
- How could this law influence the choices of **vulnerable populations**?

Second – what we don't know. We've talked about what we know about the law, so here I'll raise some of the issues we don't know.

CHI wanted to share some questions that have been raised when considering this law's implementation. They all get at the main issue that has been raised across the board, and that's how we can ensure that this law is safely and effectively implemented for all Coloradans that want access to it.

This is where I want to start triggering your questions that you have about what this law will mean for the communities that you serve, and the constituencies you represent. We'll have a brief conversation about those issues at the end of this session.

I'll just list a couple of the high level questions – this is just a beginning. For instance:

- **How will we change the way we train physicians?** Eg. Palliative care specialists are experts in having these discussions on death and dying, but they have learned to do that over years of practice. This law is an opportunity for patients and their doctors but it adds a level of complexity – resources may be required to train physicians.
- **How do we communicate with patients and our community about this?** The task of

communicating these options does not fall only on physicians. How these options are communicated more largely in our community is also a question. A strong tracking system to monitor the impact of this law – who is using the law and under what circumstances – will be important to CHI as we track how this law is implemented.

- That brings me to one final question to consider — and it’s one we thought was important to raise during this discussion since it has been voiced by both sides of the aisle. The question is **How could this law influence the choices of vulnerable populations?** This question has largely been raised with regard to populations like disabled Coloradans, high health care utilizers and Coloradans who may have fewer options on the table when it comes to health – so this question generally applies to the 353,000 Coloradans that are uninsured, the 136,000 of them are also low-income [less than 100% of the federal poverty line], and the 60,000 of them who have less than a high school diploma... so the question is whether this law will influence the choices of these Coloradans who have generally less access to care to begin with.
 - It’s important to note the eligibility criteria of the law are not different across different populations. But the question that’s been raised is if this law might influence their choices at the end of life.

Medical Aid in Dying: The Oregon Experience

SINCE 1997

1,545

Prescriptions written

991

Patients died from ingesting prescribed pills



IN 2015

218

Prescriptions written by **106** doctors

132

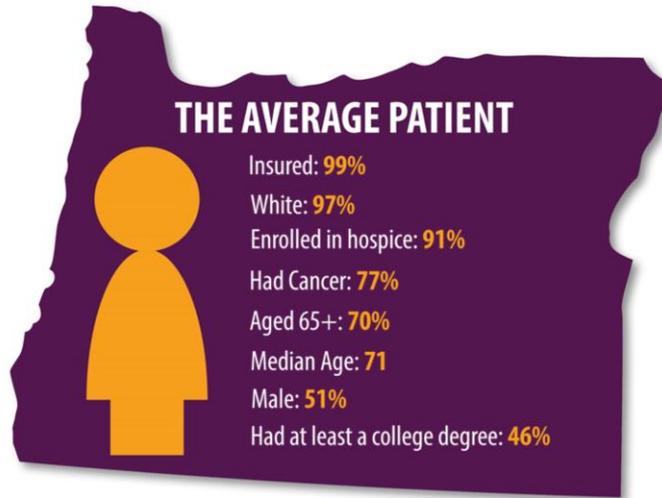
Patients died from ingesting prescribed pills

Because of their tracking data, we know a good amount about who is affected by the law in Oregon, and how many are affected.

In Oregon, 991 patients have died from ingesting medication since the law passed 19 years ago, a small percentage of the population. **That's about 64%** of those who were prescribed – and that portion has remained fairly constant over the past 10 years (**61% in 2015**).

But the number of prescriptions and prescribing physicians have increased [68 more patients received prescriptions in 2015 than the year before]

The Oregon Experience



Source: Death with Dignity (1998-2015)

We also know who in Oregon has taken the drug.

Over the past 19 years, the option has most often been used by people in Oregon with terminal cancer diagnoses – no surprises there. People using the drug also differed from the larger population – they tended to be well-educated and older – the median age at death is 71

Oregon has the most robust data currently available, but drawing conclusions from its experience can be tricky. The sample is small and comes from a relatively homogenous state population. No one is sure what might happen in larger or more diverse states.

- People using the drug also knew their prescribing physician for a median of 12 weeks
- People using the drug were insured:
 - Private: 57.2 %
 - Medicare, Medicaid, or other governmental: 41.4 %

Compared to Oregon's population in general:

- Race:

- White alone, not-Hispanic: 77.6%
 - **White (one race, not regarding ethnicity): 85.1%**
- Aged 65+: 15%
- Median age of Oregon: 38.9
- Male: 49.5% (**Percent male 65+: 45.1%**)
- **College degree (bachelor's degree or higher): 20.8%**
- Insured:
 - of 65+ population: 99.5%
 - **Total population: 85.6%**
- Cancer prevalence (2013)
 - Incidence rate: 431.5 per 100,000 or .431 percent
 - Death rate: 163.2 per 100,000 or .163 percent
- Sources:
 - Demographic Data: American Community Survey, 5-Year Estimates, Oregon, Health Insurance & ACS Demographic and Housing Estimates
 - Cancer Rates: CDC Cancer Rates by State, based upon 2000 US standard population <http://www.cdc.gov/cancer/dcpc/data/state.htm>
 - https://www.deathwithdignity.org/wp-content/uploads/2016/04/2015_ORDWDA_Annual_Report_040816.pdf?x33858
 - <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

Plan for the Hour

1. Medical Aid in Dying in Colorado
2. Experts Weigh In
3. Your Turn – What's Next?

Panel discussion:

(5 min) Megan: You've had a pulse on Coloradan voters and the legislature for a number of years as a journalist. **So can you talk about some of the challenges and opportunities that this law has raised?**

(5 min) Kat: You're bringing experience leading campaigns to implement Aid in Dying laws in multiple states including Oregon and California. **Can you talk about the experience of other states implementing these laws, and what lessons Colorado can take forward?**

(5 min) Dan: You're bringing a unique perspective to today's discussion – you're a physician and an administrator in Palliative Medicine at Denver Health. In a sense, you'll be on the front lines of implementing this law. **Given your perspective - What changes do you anticipate in the way physicians practice, the way they are trained, and the way patients access care?**

We've heard from our experts, now to you. As moderator I'll just mention that my job is to make sure we're on the task of working through what's next for Colorado as we implement this law. So if there are important issues that you'd like to address but that

we just can't address within today's discussion, I'll ask we park those questions for discussion offline at the end of the panel – we would love to hear from you.

Who has our panelists' first question?

Plan for the Hour

1. Medical Aid in Dying in Colorado
2. Experts Weigh In
3. **Your Turn – What's Next?**

Panelists join tables for discussion. Collect takeaways from the tables. Afterwards, panelists return to the front.

Your Turn – What's Next?

What questions remain for you and your constituency to ensure Colorado's End Of Life Options Act is safely and effectively implemented?

There are legislators in this room, there are health care providers and administrators, community leaders, and likely all of us in here are health care consumers.

Given your perspective and the constituency that you represent, what further questions do you have or information do you need to ensure CO's End of Life Options Act is implemented safely and effectively? We'd like our panelists to help raise some of those questions and if possible, answer some. In **eight minutes**, we'll regroup and ask you to raise a couple of those questions for the group.

After tables share out, panelists return to the front. Alex will ask for 1-2 min closing thoughts and any closing stories from panelists.



Three Takeaways

- 1 What we know about Colorado's End of Life Options Act
- 2 What we don't know about how it will impact provider training, patient communications and vulnerable populations
- 3 What can we learn from other states

Today we went through 3 things – to reiterate:

First was what we know about Colorado's End of Life Options Act.

Second is what we don't know – we started to discuss some of your remaining questions and CHI will continue to track these as the law is implemented.

And last we talked about what we can learn from the experience of other states implementing medical aid in dying laws, such as Oregon with 19 years of data to draw on.

I want to leave you with you quick things -

CHI in 2017

A Sneak Preview

- New logo
- Updated website
- Same commitment to a healthy Colorado

Alexandra Caldwell
caldwella@coloradohealthinstitute.org



Coming soon – CHI is getting a makeover! Here’s a sneak peek at some of the exciting changes in store for us in 2017.

Watch for our new website to launch at the end of January. We’ve collaborated with Open Media Foundation to refresh the design and make it even easier to find our great research, analysis and data.

And be on the lookout for our new logo created by Creative Services Director Brian Clark.

We will unveil it at the same time as the website.

UP NEXT:

3:00 p.m. – 4:00 p.m.

KEYNOTE ADDRESS TWO

Should Health Care Institutions Be the Epicenter for Health?

Patricia Gabow, M.D.

Location: Colorado Ballroom

With that, we thank you for your attention this afternoon. I'll be available throughout the conference, and a couple of our panelists will stay after (TBC). Please come find us. We'd love to hear your thoughts and questions.

You have a 15-minute break now. Come join us for Dr. Patricia Gabow's remarks back in general session room – she'll be asking the question Should Health Care Institutions Be the Epicenter for Health?

Thank you.

Backup

Finding the Words: Terms used today

- **Medical Aid In Dying:** Patient self-administers prescribed lethal medication.
- **Passive Euthanasia:** Withdrawing medical treatment with the intention that it will result in a patient's death.
- **Voluntary Active Euthanasia:** Physician actively administers life-ending medication, usually intravenously.

There is no consensus on the best term for this discussion. Supporters use phrases like “death with dignity” while opponents favor “physician-assisted suicide.”

We will use “Medical Aid in Dying” or “End of Life Options” as one of the most neutral descriptions since it avoids “suicide, dignity” – and matches the law itself.

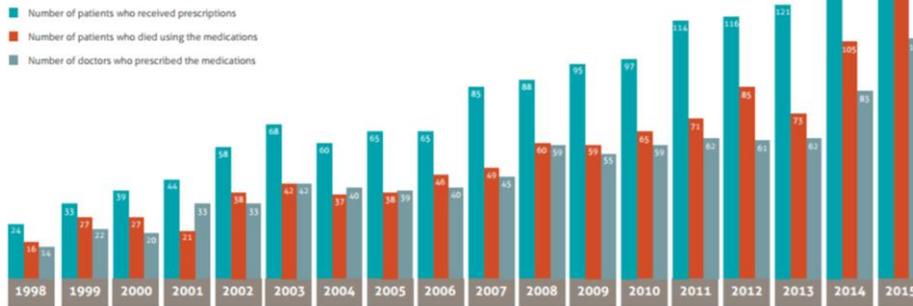
The Oregon Experience



How many Oregonians use the Act?

In late 2014, Brittany Maynard's story spiked the interest and attention in physician-assisted dying as an end-of-life option, leading to an increase in the number of Oregonians using the Act.

As in years past, one in three patients with a prescription chose not use it—testimony to the fact that merely having the option to control the manner of their death offers terminally ill people comfort.



Source:
Death with Dignity
(1998-2015)