LIVE WEBINAR SERIES

End of Life SYMPOSIUM

# Aid in Dying Medications & the Clinical Competencies of Prescribing

City of Hope

compassion & choices
Care and Choice at the End of Life

**Chandana Banerjee, MD, HMDC**

*Director & Designated Institutional Official*

*Graduate Medical Education*

*Assistant Clinical Professor, Supportive Medicine*

*Course Director & Chair, End of Life Symposium*

*City of Hope*

# Thank You!

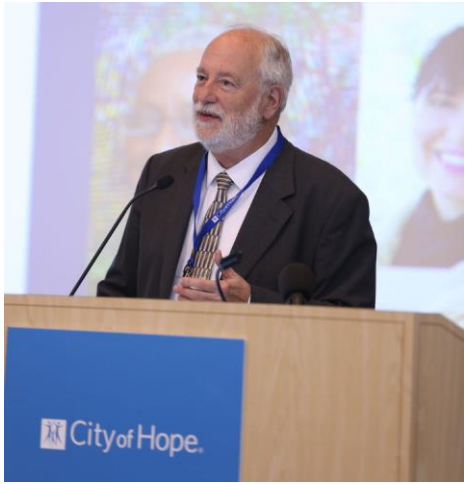

SAVE THE DATE
End of Life
SYMPOSIUM
December 16 to 18, 2021
Waldorf Astoria Las Vegas

# Today's Moderator

Matt Whitaker

C&C National Director

# Today's Speakers




David R. Grube, MD
Family Medicine (Ret.)
National Medical Director
Compassion & Choices

Susan Gess, PharmD, APh
Drug Education Coordinator
Clinical Pharmacy
Kaiser Permanente San Rafael Medical Center

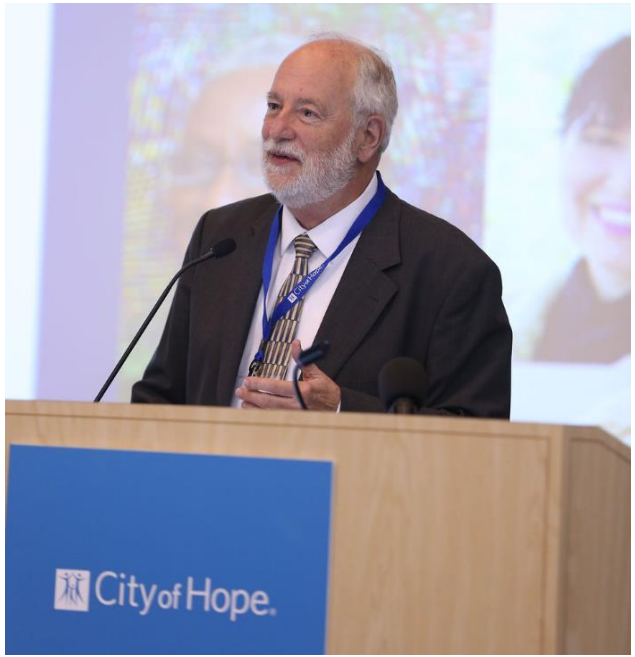
# David R. Grube, MD

Family Physician in Philomath, OR 1977 – 2012

Benton Hospice Service – Lumina Hospice
1980 – Present
BOD – Chair, Ethics Comm.

Death With Dignity (MAiD)
First request from patient in 1999
~ 30 patients from 1999 – 2012

National Medical Director C&C
2014 - Present



# Susan Gess, PharmD, APh

Over 30 years practice in Clinical Pharmacy

UCSF Medical Center
Kaiser Permanente San Rafael Medical Center

End of Life Option Act
Consulting Pharmacist since 2016 inception

# Disclosures

**David R. Grube, MD – None**

**Susan Gess, PharmD - None**

**Matt Whitaker - None**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# End-of-Life Options

- Pursuing Life-Sustaining Treatment
- Refusing Treatment
- Discontinuing Treatment
- Hospice / Palliative Care
- Voluntarily Stopping Eating and Drinking (VSED)
- Continuous Deep Sedation
- **Medical Aid in Dying**

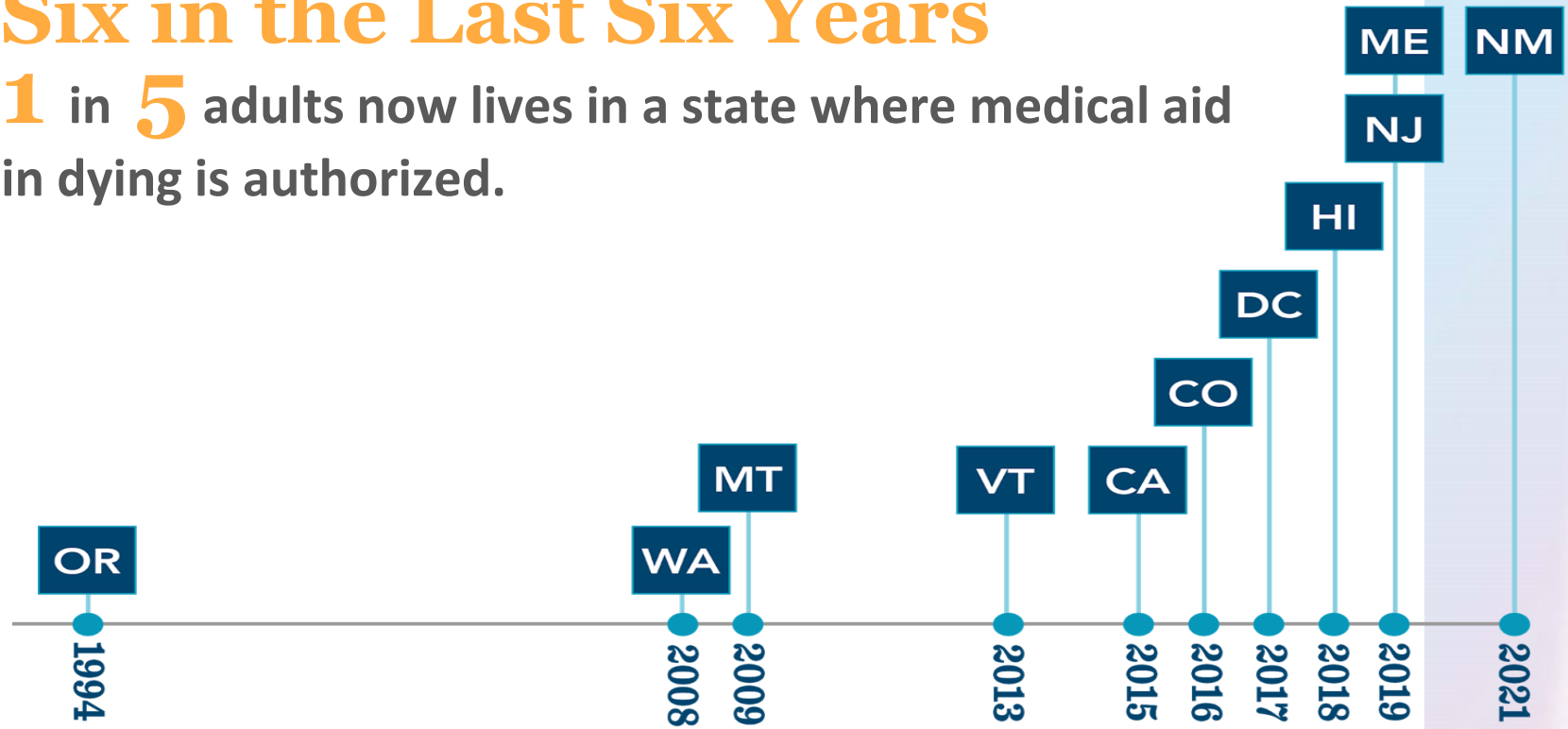
# Medical Aid in Dying

**Medical aid in dying** is a medical practice in which a mentally capable adult with a prognosis of six months or less to live may request a doctor's prescription for medication which they can choose to self-ingest to peacefully end intolerable terminal suffering.

# Authorized in 11 Jurisdictions

## Six in the Last Six Years

**1 in 5 adults now lives in a state where medical aid in dying is authorized.**



# Medical Aid in Dying
# Eligibility Requirements

- Adult / Resident
- Terminally ill

  (Prognosis of 6 months or less)

- Mentally capable of making informed medical decisions
- Able to self-ingest

# How do we respond to a request for medical aid in dying?

Be prepared:

- Education/explore personal beliefs/consults
- Listen…
- Consider context (hospice patient)
- Listen…
- Explore patient's fears/concerns/wishes/values/beliefs/ resources/relationships
- Listen
- (Possibly discuss w/ family)
- Use professional integrity: refer if unable to participate

# Provider Components

- **Prescribing Physician (“Attending”)**
  - Evaluate patient / document
  - Follow compliance process / complete forms
  - Prescribe medication

- **Consulting Physician**
  - Evaluate patient / document / complete forms

- **Psychiatrist / Psychologist / Lic. Clinical Social Worker**
  - Evaluate mental capacity to make informed medical decision (optional, but required in Hawai’i)

- **Pharmacist / Nurse / Social Worker / Chaplain**

# Important Reminders

**Language matters**

Use non-judgmental and kind words

Medical Aid in Dying is appropriate language

Medical Aid in Dying is not suicide

**Death Certificate**

Public record to establish estate and for epidemiology

Cause of death is the disease (Lung Cancer, ALS, etc.)

Requests for medical aid in dying do not reflect a failure of palliative care

**Mental health evaluations** are rarely necessary

# Medical Aid-in-Dying Medication

- The type and dosage of aid-in-dying medication prescribed for the terminally ill person can vary with each individual.
- After self-administering the medication, the person usually falls asleep with 20 minutes and dies painlessly and peacefully within an hour or two.

Note: Providers who contact C&C Doc2Doc consultation line can request medication regimens and a list of participating pharmacies

# History

- 10 Gm **secobarbital** (capsules) or 10 Gm **pentobarbital** (powder)
- Pentobarbital not available ~ 2013
- Price of secobarbital increased from ~ $200 to $3,000 ~ 2015
- Secobarbital no longer available – 2019
- Varied protocols (chloral hydrate, phenobarbital, amitriptyline, liquid morphine, combinations)
- **DDMP:** Digoxin 50 mg, Diazepam 1 gm, Morphine 15 gm, Propranolol 2 gm.
- **DDMP2:** As above, but Digoxin increased to 100 mg
- **DDMA, D-DMA**
- **? DDMAPh, D-DMAPh, 1/2D-DMA (w/ clarithromycin)**

# **Protocols** (5/2021)

- **DDMA**: Digoxin 100 mg, Diazepam 1 gm, Morphine 15 gm, Amitriptyline 8 gm.
- **D-DMA:** As above, but digoxin is given separately, 30 minutes before the other medications.
    - Shavelson/Parrot, ACAMAID
- **DDMAPh:** Digoxin 100 mg, Diazepam 1 gm, Morphine 15 gm, Amitriptyline 8gm, Phenobarbital 5 gm.
- **D-DMAPh:** As above, but digoxin is given separately, 30 minutes before the other medications.

# Medications: D-DMA

- ❑ NPO for 4 – 6 hours (no dairy, no heavy laxatives)
- ❑ Take usual medications

**One Hour Prior**

- Ondansetron 8 mg
- Metoclopramide 20 mg

**One Hour Prior**

- Ondansetron 8 mg
- Metoclopramide
- Diazepam 1 Gm

**Ingestion**

- Morphine Sulfate 15 Gm
- Amitriptyline 8 Gm

# DDMAPh, D-DMAPh

- Addition of 5 Gm of Phenobarbital
- ACA MAID
- 52 Patients
- Shortens average length of time to death
  - 1.2 hours (from 1.5 hours)
- Upper range of times to death also shortened

  5.1 hours (compared to 12.5 hours)

https://www.acamaid.org/wp-content/uploads/2021/01/Adding-Phenobarbital-to-the-D-DMA-and-DDMA-Medication-Protocols-for-Medical-Aid-in-Dying-1-1.pdf

# Red Flags

- **GI Absorption** issues:
  - GI Malignancy; Swallowing Concerns;
  - Gastroparesis; Cachexia; Bowel Obstruction;
  - Tense Ascites
- **CV Wellness** (Younger patients with ALS)
- **Obesity** (> 300 pounds)
- **Alcoholism**
- **Tolerance** to Opioids/Benzodiazepines

# Barriers

- Complexity of MAiD process (variable by jurisdiction)
- Currently MAiD prescriptions must be obtained at a compounding pharmacy
- Cost (lack of Federal/Medicare Insurance)
- Some pharmacies owned by faith-based organizations
- Some pharmacists will not dispense

**My Sister Ra Died a Hero**, Hazzard W, *J Amer Geriatrics Society*, 2016, 02-8614

- Waiting periods (KP ~ 30% in CA die during process)

# Health Insurance

**Federal prohibition:**

- Medicare
- VA

**Most private insurance and MediCal cover Rx**

# Pharmacist Consultation Medical Aid in Dying

Susan Gess, PharmD, APh

# A little context . . .

- Serve in an integrated health care system
- End of Life program:  Physician Leads, Program Coordinator and Patient Coordinators, Pharmacist

- All participation voluntary
- Multiple “Schwartz Rounds” allowed providers to share feelings about the law, nervousness participating, barriers

- Pharmacist appointment with patient coordinated through the Patient Coordinators
- Pre-COVID:  Pharmacist hand carried medication set to parent for home visit.  Currently:  Courier delivers medications prepared at designated pharmacy and pharmacist performs video visit or telephone visit

# Support Materials are Critical

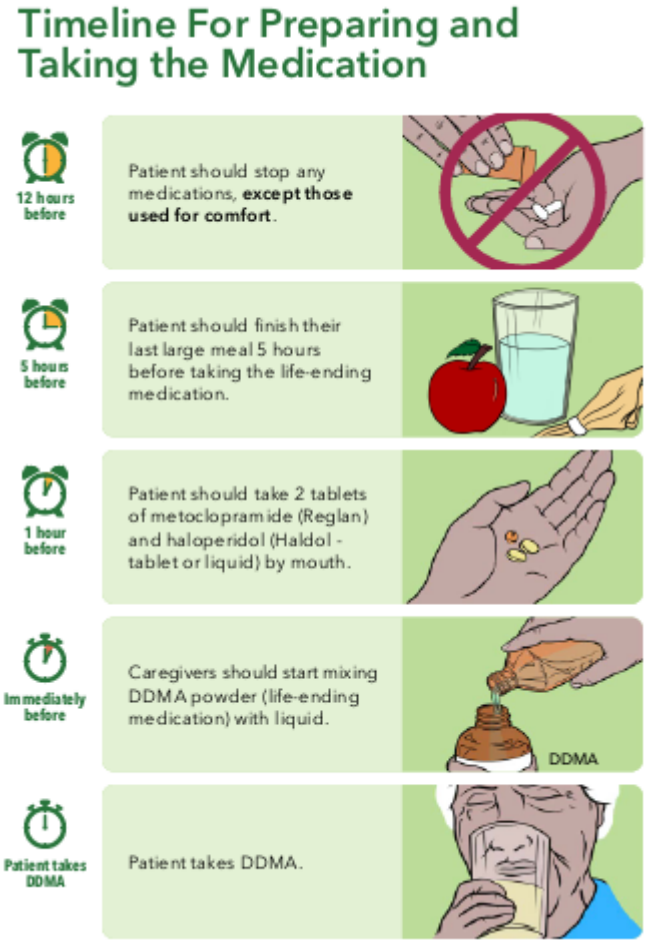
- **Patient brochure**
  - Timeline - pictorial version
  - Timeline verbal (opposite page)
  - Helps guide consultation
- **Pharmacist education and information sheet**
  - Time to death summaries
  - Expected phases of death process
- **Standardized note for charting**
  - electronic health record

# Comfort Level

- Shadow with an experienced pharmacist (with patient permission)
- Have good supporting materials and feel knowledgeable about drugs, how they work, dying process

Online guidance: https://endoflifewa.org/wp-content/uploads/2020/02/Preparations-for-the-Last-Day-Feb-2020.pdf

- Are you drawn to work in this setting? – not for everyone




# Topics Covered in Consultation

- Purpose of the visit/consultation
- Review the medication instructions
- Time sequence for administration
- What to expect
- Safety, storage and disposal
- Patient handout
- Average consultation: 20-30 minutes

# Variations in drug regimens / supplies

- **Life ending mixture**
  DDMA, D-DMA, DDMAPh
  Powder for admixture* - 6 month expiration
  Premixed liquid - 2 week expiration
- **Premeds**
  Omeprazole, Haloperidol, Metoclopramide
  Tablets (can be crushed) or liquids
- **Administration supplies**
  Measuring bottle
  Straw
  Syringe
- **Instructions**
  Critical support to verbal instructions


* crushing tablets not recommended - adds a large volume of inert powder and longer time to death

# Considerations

- **MD call to pharmacist directly helpful**
  - Let them know prescription on the way
  - Make sure questions are answered up front

- **Ingestion factors to consider**
  - Feeding tube / Rectal catheter administration
  - Liquid versus powder preparation

- **Order 2-3 days in advance of need**
  - May need to get specific medications ordered into stock

- **Cost:  ~$750**

# Standard kit provided to patient

- Three medication containers (with instructions):
  - 8 oz. glass amber bottle containing DDMA powder
  - 2 tablets of metoclopramide 10 mg
  - 1 tablet of haloperidol 2 mg
- Pharmacy amber 4 oz. bottle (as measuring device)
- Wide bore drinking straw
- Syringe included if G-tube/PEG
- Patient consultation packets (2)
- Self-addressed, postage-paid Take-Away bag (for disposal)
- Medication response card


*DDMA - diazepam 1 gm, digoxin 100 mg, morphine sulfate 15 gm, amitriptyline 8 gm

# What to Expect After Ingestion of DDMA

| | Timeline | Notes |
|---|---|---|
| **Sleep** | 2 to 40 minutes after taking the medication | After taking the medication, drowsiness occurs. This is soon followed by a deep sleep (loss of consciousness). |
| **Coma** | Minutes to hours after taking the medication | Deep sleep progresses to coma. Breathing slows and often becomes irregular. Periods of shallow and deep breathing may occur. |
| **Death** | Within 8 min to hours after taking the medication | Average time to death ~2 hours<br>Range: 6min – 12 hours<br><br>Warn rare cases - chance of extended coma before dying.<br>[Noted risk with high opiate doses, impaired gut motility, severly obese. May anticipate and add phenobarbial to regimen] |

# COUNSELING POINTS / PATIENT QUESTIONS

**PROVIDE THE "WHY "**

| | |
|---|---|
| DDMA mixture must be ingested within 1-2 minutes | Will fall asleep quickly – need to get in full dose<br>Would not want them to fall asleep before getting the full dose<br>Can practice with 3 oz water in advance to test ability |
| Premedication is an important step 1 hour prior | Metoclopramide :<br>- Helps gut motility to get drug where it needs to be absorbed<br>- help prevent nausea |
| What is this DDMA mixture and how does it work? | Diazepam (Valium) - - Slow breathing (respiration)<br>Digoxin - - Slows heart rate (used with patients with afib)<br>Morphine - - Pain medication that slows breathing and heart rate<br>Amitriptyline - - Also affects the heart (causes heart block, etc) |
| What will the mixture be like and taste like? | - Mix with clear juice<br>- Will be milky white and a bit gritty<br>- Can chase with sorbet to mask bitterness<br>Alternative option - Alcohol chaser – assess seizure risk |

# Amitriptyline and “burning”

- **Amitriptyline may cause mild symptoms of oropharyngeal ‘burning’**
  - Noted as severe in ~10% of patients
- **Patient should be warned in advance**
  - Calm reassurance and expectation can decrease symptoms
- **Pausing or stopping may increase mucosal exposure**
- **Spoonful of sorbet can resolve symptoms**
  - Loving effect when administered by family
  - Cool and soothing
  - Sorbet non-milk containing so no interference with drug absorption
  - Helps with bitter taste of the overall mixture

# Other helpful tips for patients / families

- **Positioning**
  - Best if sitting or slightly upright - avoid regurgitation
  - Place of preference - garden, favorite chair
- **Ensure no interuptions**
  - Make sure all goodbyes are said
  - Don’t want interruptions during the process
- **Trial run of 3 ounces liquid**
  - Reassure that they can drink within 1-2 minutes
- **Peaceful passing for the patient - no pain**
- **Dispose of unused medications safely**

# Varying Experiences

- **Different Pharmacist styles**
  - matter of fact
  - emotionally supportive

- **Be ready for different patient reactions**
  - straightforward little emotion
  - often a lighter atmosphere than you might think
  - need some time as reality sinks in

    "It becomes very real when you get the medications in hand."
  - very emotional

    "It's okay. I can wait until you are ready."

Note: You can be professional and still tear up.

# The Rewards

- **Providing people with a choice**
  - more than 30% of patients never ingest, but feel relief just having medication available
  - number one reason patients' list for choosing MAiD is fear of losing autonomy
- **Supporting both the patient and the family**
  - Information
  - Emotional support (takes many forms)
- **Some of the most meaningful work you might ever do**

# Patient Case:
## Questionable mental clarity at consultation

Wife confirmed patient ready for consult via early am phone call
Pt in hospital bed in entry room/living room - completely unarousable

**Can you leave the medications with the wife?**

- by law, need to consult the patient directly
- patient needs to submit last consent/attestation

Upon further questioning . . .

- Hospice administered lorazepam night previous and increased pain medication from which patient has not aroused.
- Reason for increased meds → patient disoriented from pain and cornered wife in bathroom doorway with knife