



End of life Issues



Continuum of Care Project

Alya Reeve, MD, MPH
Lourdes Vizcarra, MD
Ingrid M. Nelson, MS

University of New Mexico
Health Sciences Center
Department of Pediatrics

January, 2012



Objectives

2

- **This Training will explore:**
 - a) The importance that values, attitudes, etc. have when supporting the (dying) patient.**
 - b) Who has the legal right to make healthcare decisions.**
 - c) Death/Dying as a (natural) process.**
 - d) Awareness of the impact that death, dying, and mortality reviews have on the advancement of clinical knowledge.**

Know Thyself

3

Examine your own philosophy on

- Life
- Health
- Quality of life
- Sickness
- Getting Older
- Terminal Conditions
- Death

Know Thyself

4

Your philosophies or belief systems will impact your approach with delivery of care and how you advocate for your clients.

Get the paperwork in order & update as needed...for Advocacy

5

- **Advanced Directives, Living wills**
- **Power of Attorney**
- **NM Uniform Healthcare Decisions Act - Surrogates**
- **Guardianship**
- **Five Wishes + My Wishes**
- **Decision Consultation Form**

Capacity

6

- As addressed in the Uniform Health-Care Decisions Act, **capacity** refers to
 - an individual's ability to understand and appreciate the nature and consequences of proposed health care,
 - including the significant benefits, risks and alternatives to proposed health-care
 - and to make and communicate an informed health-care decision.

Capacity

7

- Refusing treatment is not a determinant or indicator that the individual lacks capacity.
- Lack of capacity cannot be based solely on patient's disagreement with the doctor.
- Determination of a lack of capacity, according to the UHDA, requires
 - 2 professionals make an assessment-
 - one of whom must be the PCP
- When mental health or I/DD is present
 - At least one of the health care professionals must have expertise in assessing functional impairment

Paperwork...

8

- Advance health-care directive-
 - is an individual's instructions as to the kind of medical treatment s/he would or would not want in the event that s/he becomes incapacitated or unconscious or so ill that s/he is unable to express health choices or wishes
- A person has to have capacity in order to have an Advance Directive

Paperwork...

9

- ⦿ Think of an Advance Directive as an autobiography - it must be written by the originator otherwise it is not an auto (self) biography
- ⦿ So...no one can write an Advance Directive for you...only you can write one for yourself...as long as you have capacity (or your wits about you)
- ⦿ Think of a biography - as a healthcare decision- which is written by another, about/for you
- ⦿ A surrogate decision maker (POA or Guardian) can make decisions for you as long as he/she has capacity (or they have their wits about them)

Don't Get Confused

10

“Advance Directive”

(the form with this name on the top)

Through this form, you can name an Agent or Attorney – in-fact (POA). The Agent will make healthcare decisions for you. However, this form does not need to be notarized.

[It makes sense - as this form is a requirement at hospitals and surgery cannot be held up because we are waiting around for a notary.]

Copy is as good as the original in New Mexico.

More Paperwork

Don't be confused

11

“Power of Attorney”

(the form with this name on the top)

Through this form, you, the Principal, can name a person (Agent or Attorney-in-fact) to take care of your affairs which covers two categories:

- Healthcare
- Finance or business

More Paperwork...

Don't be confused

12

Best option is to have a “durable” POA or one that states “...this document will not be affected by my incapacity...” so, if you should lose your wits about you, the document is still in effect, otherwise it would be null and void.

However, for Finance- this form must be notarized in order for it to be a legal document. For Healthcare- witness & notary is recommended, *but not required.*

Paperwork...POA

13

The person initiating this document (Principal) has to have capacity at the time that these papers are signed

The majority of POAs are activated when a person loses capacity (e.g. coma, surgery, recovery, dementia, etc)

Paperwork...POA

14

- Powers of Attorney *can* start immediately but the Principal decides by indicating such-when completing the form

(this option is often chosen when the Principal is in a serious or terminal condition).

Paperwork...POA

15

- **Keep in Mind**

There is no POA that governs or takes away a person's civil rights, rights to privacy, etc.

No POA for: morals, who can date whom, what the Principal can spend his/her money on, etc.

Paperwork - POA

16

The Principal should not complete this form under duress, threat, seduction or coercion

Principal is in the driver's seat - This information is not emphasized enough

POA can be revoked at anytime *by the* Principal

Updates should be given to those who need to know w/new Agent named, etc.

Paperwork - Guardians

17

- A guardian is a person appointed by the court to make personal and health care decisions for a person (the ward) who has been deemed “incapacitated.”

- Guardianship is governed by the State Probate Code

- Types of Guardianship

- Full or Plenary

- Limited

- Treatment*

- Temporary

- Guardian ad Litem

* *Mental Health & Developmental Disabilities Code*

Paperwork - Guardians

18

- Average cost - \geq \$3,200 (uncontested)
- Testamentary - \geq \$300
- Those who seek to be a guardian, but fall below the poverty line–
 - Contact the Office of Guardianship to get on the waiting list for the Guardianship Program where the fee is free or nominal
 - 1-(505)- 476-7321 or 1-(800) 311-2229
- Contact: Christine Wester, LBSW, MPH
 - IAA/DRP Unit -1-800-283-5548 or
 - Albuquerque (505) 841-5529

Surrogate Decision Makers

19

- An individual, other than a patient's agent or guardian, authorized under the NM UHDA to make health-care decision for them.
- Surrogate can be appointed if the agent is not “reasonably available” and there is an urgency in treating the health-care needs.
- Alternates can also be chosen based on their availability and willingness to be a surrogate.

Hierarchy of Surrogates

20

- Spouse
- Significant Other
- Adult Children
- Parents
- Adult Siblings
- Grandparents
- Person showing Special Care



More on Surrogates

21

- **DDSD Form:**
 - Documents that a surrogate has been identified to take on the role as decision maker
- **Temporary –**
 - in cases of serious/ delicate medical situations when a decision is needed
- **Surrogate should also be actively pursuing guardianship if it is determined that the individual lacks capacity**
- **Questions?**
 - Please contact Christine Wester, LBSW,MPA at the IAA/DRP Unit (see resources)

Paperwork... Five Wishes 1-888-5-Wishes

22

- ◎ Holistic document honored in many states (e.g. New Mexico) which gives you the opportunity to capture your healthcare wishes and needs in a way that lets others know officially:
 - ◎ What procedures you want or don't want
 - ◎ Who you want to make decisions for you
 - ◎ Comfort Measures

Paperwork...1-888-5-Wishes

23

- ⦿ Preferred approach
- ⦿ What you want friends and family members to know
- ⦿ How you would like to be treated

Note: [Copyright regulation -Original Five Wishes Form! (can make copies of completed form for family, etc.) Can replace old AD, living wills as long as you tear up the old and alert PCP, etc.]

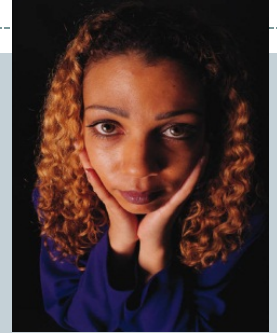
Additional form for Consideration

24

- ***My Wishes* is based on the Five Wishes**
- **For Children/Minors**
- **Does not require signature and is not a legally binding document**
- **Addresses how one wants to be treated and this completed form can be shown to family, friends, healthcare professionals and IDT members**

Decisions are based on beliefs, attitudes...

25



- **Healthcare Decisions are often Value-driven**
- **Recognize and respect the cultural, religious and social differences**
- **Quality of life should be at the forefront**
- **Individuals must be treated with dignity and respect...regardless!**

Decisions, Decisions are Value-based

26

- **Gently initiate discussions which allows the individual to share his/her perspectives and values**
- **The Values History Form**
 - can be used as a means of getting to know the whole person
- **Don't wait for matters to be serious to engage in this conversation**
- **Listen...**
 - Yet refrain from being critical if the individual's values are not complimentary to yours.
 - *Do* ask questions when seeking to genuinely understand

Decisions, Decisions

27

- ⊙ **Check documents when surrogate decision makers are claiming they have the authority**
 - ⊙ **Use common sense!**
- ⊙ **Individuals and surrogates (POA, Guardians) should have full access to disclosure of medical information**
- ⊙ **Healthcare Decisions are made by the Individual w/capacity, guardian, POA agent or Surrogate**
 - ... not by the Inter-disciplinary Team members!**

Next Phase for Advocacy

28

- Getting to the point where you are comfortable with Individuals whose medical condition becomes complex, chronic, very serious or even terminal



Advocacy - Food For Thought

29

- ⊙ Understand the law to protect clients' & others' right(s).
- ⊙ Know that the Individual will experience a kaleidoscope of emotions, moods, feelings...be prepared.
 - ⊙ Be supportive, patient and be willing to endure.
 - ⊙ Support, patience, and endurance are at the core of advocacy
- ⊙ Individuals may alter their beliefs, they may go in and out of consciousness, show signs of dementia... *Can you handle it?*

Food For Thought

30

- Educate care-givers, family and team members- so that they also are acting in the best interest of the individual
- Most actions are done with good intentions, but not all decision makers are “in the know” or are operating within the realm of their responsibilities
- Don’t give power beyond what the law permits- and *never* at the expense of the individual!

*Resources...
in conjunction with DDSD Regional Office*

31

- Medical Consultants (Regional)
 - Continuum of Care
- TEASC & Special Needs Clinics
- HDR (Healthcare Decision Resources) Committee
- Ombudsman -Long-term Care
- Hospice
- Ethics Committee- at each Hospital
- Resource Center

The road ahead...

32

Know the laws and who has the right to make healthcare decisions...always do the Right Thing!

Invite healthcare professionals to IDT meetings so that medical complications can be explained (via phone, video conferencing or written response to specific questions/concerns)

**Understand that it ain't easy being a healthcare decision maker...nor a Case Manager, Nurse, etc.-
*empathy please!***

Work towards finding a good plan for carrying out the healthcare decisions

The road ahead... This may be in the mix

33

- ⊙ Do Not Resuscitate (DNR) or In-tubate (DNI)
- ⊙ These are special orders and please note that they cross categories
- ⊙ DNR/DNI orders, when initiated by a person with capacity, it is *part of an Advance Directive*
- ⊙ However, when a Surrogate Decision Maker initiates a DNR/DNI order, for another, it is a *healthcare decision*
- ⊙ *DNAR* - *Do Not Attempt Resuscitation or*
- ⊙ *AND* - *Allow Natural Death*

The road ahead... This may be in the mix

34

- ◎ **Standardized EMS -DNR Form**
- ◎ **Only form they will honor**
- ◎ **Place it where it is conspicuous, freezer/bag, carry order w/you (medical bracelet) Copies are OK.**
- **Most hospitals will only honor standard DNR Forms from a physician's office; so both forms may need to be used: one for EMS and one for the hospital (upon admission)**
- **All DNR orders must be signed by a physician**
- ◎ **This may be a bitter pill for some staff/teams**

Decision Consultation Form

DOH developed form

Refer to DDSR
Regional Office for
questions

DOH Web * Standards

Empowering document when used efficiently – each time a difficult medical decision is made; form should be completed entirely with pertinent information - outlining discussion, options and decision by whom- relationship to Individual

- **Case Manager generates, completes and submits this form**
- **Assistance: from nurse on medical component or IDT member with the most information**
- **Captures key points of meeting(s) indicating that condition was discussed, options were considered and this is the choice that the legal decision maker (e.g. Guardian, unadjudicated Adult) has made**
- **Stand alone document**

The road ahead...

36

Team members may have to disengage themselves if they cannot ethically support a healthcare decision (discuss w/supervisor, DDSD, standards, etc.)

Meet as often as needed for planning and updates - keep team members focused on quality of care

Meet when new interventions are put in place (e.g. hospice, long term care, SNF/NF, etc.). Discuss who will cover what, who the point person will be, which conditions are under the guidance of which entity...examine all areas to exhaustion...then exhale.

DOCUMENT, DOCUMENT, DOCUMENT!!!!!!

Dying is a (Natural) Process

37

- **Cognitive understanding**
 - Meaning of death, or dying
 - Awareness of world changes
 - ✦ May remain very lucid
- **Physical capacities**
 - Signs and symptoms that require different supports
 - Organs change at different rates
- **Spiritual connections**
 - Connections with present world
 - Connections with spirit(ual) world

Cognitive aspects of death

38

- **Meaning**
 - Quality of Life – engaged in living
 - What death means
 - What dying and illness mean
- **Awareness of self**
 - How is it expressed – avenues to recognize expression
 - As increase physical impairment, not necessarily have same level of mental disengagement
- **Awareness of environment**
 - Response to others, temperature, noise, activities
 - Withdrawal from direct interactions

Physical Symptoms: Assist with Patient Comfort



- **Nausea**
- **Constipation**
- **Vomiting**
- **Fever**
- **Dyspnea**

Physical & Mental Symptoms



- **Sleep problems**
- **Agitation**
- **Weakness & fatigue**
- **Anorexia**
- **Anxiety**
- **Fear**
- **Depression**

Physical Symptoms



- **Xerostomia (dry mouth)**
- **Pressure Sores**
 - **Caused by effect of gravity on the body against surfaces, or actual friction**

Symbolic Nature of food & nutrition



- ❖ **Good appetite = Health & vitality**
- ❖ **Offering food = Love & affection**

- ❖ **Poor appetite = Sick & frail**
- ❖ **Refusing food = Rejection & leaving**

Physical Capacity



- **PAIN !!!***
 - **Is the 5th Vital Sign**
 - **Everyone has a right to good pain control**
 - **“PAIN is what the patient says it is”**
 - **Pain is an ever-present ordeal affecting all aspects of living**
 - **Cuts people off from even the simplest pleasures in life**

Pain Control



○ ABC Pain Assessment

- ✦ **Ask** about pain routinely
- ✦ **Believe** the patient's report of pain
 - Most of the expected autonomic responses seen in acute pain may not be present in chronic pain
- ✦ **Choose** pain control options that are appropriate for the patient, and family, per doctors orders.

Pain Control



- **Massage**
 - Attend to muscle tension, circulation
- **Change positions**
- **Heat**
 - Warm compresses to the painful site (moist heat)--- requires a doctors order
- **Bath -- warm soaks**

PAIN ASSESSMENT SCALES

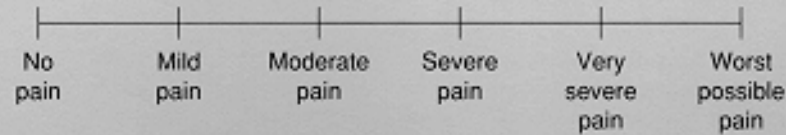


No pain

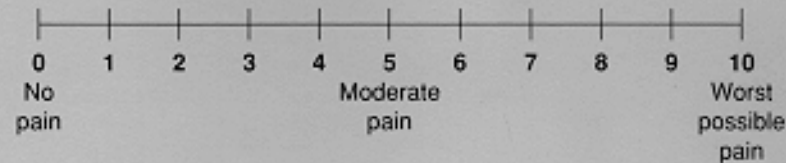


Worst possible pain

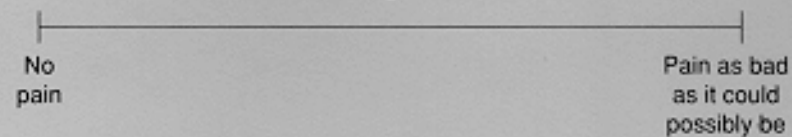
Simple Descriptive Pain Intensity Scale



0-10 Numeric Pain Intensity Scale



Visual Analog Scale (VAS)



Environmental Comforts



- **Individual preferences should be identified and honored:**
 - Who do they want near them
 - What do they want to be around
 - When are they ready (for change...)
 - What are their spiritual preferences

Emot./Environ. Comforts

- **Arrange room so person can see into common area & out of a window.**
 - Isolation is a common fear for the dying.
 - Make sure the pt. can ring for help -- bell, monitor, etc
- **Normalize the space**
 - make a comfortable, easy to get around & non-medical.
 - ✦ If medical equipment needed-try to keep out of sight if possible
- **Privacy is important**
 - Make a space available for person to meditate, pray, release emotions.
 - ✦ Staff needs a private space to release emotions also!

Emot./Environ. Comforts



- **Pets**

- if pets can be allowed in environment they often provide great comfort to the dying person.
(sometimes therapy dogs/pets are permitted)

- **Favorite Music**

- E.g.: sounds of nature; silence; spiritual music; tape recordings of loved ones

- **Remote control (if feasible) to allow person to create/control their environment.**

Emot./Environ. Comforts



- **Respect Boundaries**
 - The dying person is losing control over many things in their life.
 - Respect whose “space” you are in.
 - ✦ **Ask if the person would like you to knock before entering.**
 - Find a system that makes the person feel safe and the least invaded!

Impending Death



- **Changes in breathing**
 - Shallow, inefficient
 - Cheyne-stokes; agonal
- **Disengagement**
 - Withdrawal from active participation
- **Odors**
 - Sweet, perfume-like
 - Bodily fluids usually decline
- **Terminal events**
 - Gasps; involuntary muscle twitches; eyes.

Clinical Knowledge

52

- **Empirical basis of learning**
 - Setting standard for practice
 - Need to care for patient and supports
- **Forward-looking**
 - Life continues
- **Learning from experience and mistakes**
 - Autopsy and Review of events
- **Compassion**
 - Care for emotions of all involved
 - Need to learn for future situations

Death as a terminal event

53

- Often a delicate topic; some cultures broach gingerly
 - Discussing before-hand with your agent, executrix, etc. removes the guess work and preserves the tender moments
 - ✦ i.e.: closure without the ugliness of meetings or scrambling to get things in place.
- Once you do have everything in place...
 - Continue to communicate and update and document
 - ...and your last thought won't be, "if only I had..."
- Quality of care for the individual who is dying, until their last breath is taken.

Assuring safe passage

54

- **Identify and respect religious or spiritual requests**
 - Ascertain if there are funeral plans or burial fund in place
- **Connect with POA or Conservator (Guardian) to confirm that financial affairs are attended to**
 - In regards to the funeral costs, spiritual requests
 - What to do with the belongings (secure heirlooms or precious items)
- **Once death certificate has been signed (by M.D.),**
 - Establishments and agencies will need to be notified
 - ✦ Community connections, newspaper announcement, funeral arrangements, friends and co-workers.

Grief & Bereavement

55

- **Grief** - intense emotional suffering caused by a loss, disaster or misfortune; sorrow (Webster Dictionary)
- *Grieving* is the process of emotional and life adjustments one goes through after a loss.

Grief & Bereavement

56

- **Anticipatory Grief** - caused by an impending or upcoming situation or expected loss.
- **Bereavement** - grieving after a loved one's death

Movín' on

57

- There is no right way or wrong way to grieve
 - May go through an array of extreme emotions and reactions
- Grieving takes *time* for most people -
 - There are no correct timetables
- Meet with team members so that there is closure, but don't allow blaming to be the focus

Worden's: 4 Tasks of Mourning



- **T: to accept the reality of the loss**
- **E: experience the pain of the loss**
- **A: adjust to the new environment without the lost object (person)**
- **R: reinvest in the new reality**

J. William Worden, Grief Counseling and Grief Therapy

Mourner's Bill of Rights



- **Recognizing these rights makes healing possible**

Healing

60

- It is much healthier to go through this process in an intentional way

(Sharon O'Brien, about.com)

Healing

61

Some Suggestions:

- Learn to accept that your loss is real
- Make it OK to feel the pain
- Adjust to not having that individual in your case load
- Our clients do impact our lives and vice versa

You are not alone

62

- ⊙ Take good care of yourself...you have gone through a lot!!
- ⊙ Get good sleep
- ⊙ Eat well
- ⊙ Take breaks during work, meditate, pray, etc. – calm/soothe the mind and body
- ⊙ Exercise – take long walks
- ⊙ Talk about this experience with a confidant
- ⊙ Remember that you are in the clients/individual's life for a reason...there are no accidents
- ⊙ Be good to yourself. Gather strength, take a deep breath...you have other individuals who need you

You are not alone

63

- ◎ Ascertain that all paperwork is complete
- ◎ Possibly check-in w/family after a couple of weeks have passed
(optional, but it makes good sense)
- ◎ Hospice can be helpful with Grief counseling for the family and staff
...utilize this service!

Learning from death

64

- Keep an open mind to feedback as this may not be the only time you go down this road.
- Review events, communication, paperwork, intentions, and outcomes
- **Mortality Review process:** [especially Jackson Class members]
 - All documentation
 - Life history
 - Multidisciplinary
 - Summary conclusion
 - Open accountability

Learning from death

65

- **Autopsy**
 - Medical procedure (Office of the Medical Investigator)
 - Macroscopic, microscopic tissue examinations
 - Toxicology
 - Brain development; unusual conditions
- **Quality Improvement**
 - Identification of specific errors
 - ✦ One time event
 - ✦ Agency, System-wide barriers or habits
 - Policy changes
 - Educational opportunities

Learning from death

66

- **Case histories**
- **New syndromes**
- **Change in procedures**
- **Medical errors**
- **Improved communication**
- **Shared humanity**

Conclusions

67

- **Living is a terminal adventure.**
- **We affect others with our values and attitudes, and are affected in turn by the people we love and care for.**
- **We (individually and collectively) can assure that people die with dignity and respect in accordance with their wishes and rights.**
- **People who make healthcare decisions must be involved appropriately, frequently, and repeatedly to assure best outcomes.**

Conclusions

68

- **The dying process (short and long) affects the organs of the body at different rates, resulting in multiple symptoms.**
- **Treatments include specific therapies to the person and to the environment.**
- **Clinical knowledge will continue to evolve and improve from our examination of all aspects of the events and process involved in the end of life.**

Thank you for
your attention and participation!

