



## Continuum of Care Project

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# *Connecting The Dots to Advocacy II*

Planning can help make  
the years... tender



# Topics and Discussions

- \* Know Thyself
- \* Get the healthcare paperwork in order...and keep them in order
- \* Decisions and Decision Makers
- \* Resources (Ombudsman, etc.)
- \* Hospice
- \* Grieving & Movin' On
- \* Supportive Perspective- when advocating -you are never alone

# Introspection

If you don't know how to play the piano, how can you give piano lessons?

Examine your own philosophy on

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

# Introspection

If you don't know how to play the piano, how can you give piano lessons?

Your philosophies or belief systems will impact your approach on the delivery of care and how you advocate for your clients- directly or indirectly.

# Keep up with paperwork re: decision making ...Capacity required

- Advanced Directives, Living wills
- Five Wishes
- Power of Attorney
- NM Uniform Healthcare Decisions Act -  
Surrogates
- Guardianship

# Capacity

- As addressed in the NM 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

- Because an individual refuses treatment is not a determinant or indicator that the individual lacks capacity
- Nor can a lack of capacity be based solely on patient's disagreement with the doctor
- Determination of a lack of capacity, according to the UHDA, requires that 2 healthcare professionals make an assessment- one of which must be the PCP
- If there is a mental health or developmental disability, one of the health care professionals must have expertise in assessing functional impairment

# Paperwork...

- **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 sign an Advance Directive (*sound mind & body*)**



# Keep in Mind...

- ⦿ 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 healthcare decision- as a biography - 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

## “Advance Directive”

(the form with this name on the top)

Through this form, you can name a Power of Attorney (POA). The POA 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

# Five Wishes

- ① 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:
- ② Who you want to make decisions for you
- ③ What procedures you want or don't want

# Five wishes:1-888-5-Wishes

- ① Comfort measures
- ② Preferred approach
- ③ Messages to Loved Ones

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

# Don't be confused

## “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

# Don't be confused

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.

For Healthcare- witness & notary is recommended, **but not required.**

However, for Finance- this form **must be notarized** in order for it to be a legal document.  
Since 2007 all financial POAs are Durable

# Paperwork...POA

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.)-safety net

Powers of Attorney can start immediately, but that is *usually* done when the Principal is in a serious or terminal condition

- the Principal decides by indicating such- when completing the form

# Paperwork - POA

The Principal should not complete this form under duress, threat, exploitation 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, effective date, etc.



# Surrogate Decision Makers

- An individual, other than a patient's agent or guardian, authorized under the UHDA to make a health-care decision for the patient
- 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

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



# Paperwork - Guardians

- ◎ A guardian is a person appointed by the court to make personal and/or health care decisions for a person (the ward) who has been deemed “incapacitated.”  
Conservators» finances
- ◎ Guardianship is governed by the State Probate Code

# Paperwork - Guardians

## ◎ Types of Guardianship

Full or Plenary

Limited

Treatment\*

Temporary

Guardian ad Litem

\* *Mental Health & Developmental Disabilities Code*

# Paperwork - Guardians

- **Full or Plenary** –responsible for making all major decisions for the ward. Functions under New Mexico Uniform Probate Code
- **Limited** –This is granted when the ward can make some decisions, but not all. Court order will specify
- **Temporary** – Usually appointed for 60 days and is initiated if the physical health of the person is in jeopardy. Can be extended via the court for 30 days

# Paperwork - Guardians

- **Treatment Guardian** - at the request of a facility or treatment center, to assure compliance with medication and to make decisions regarding mental health issues. Functions under the *Mental Health & Developmental Disabilities Code*
- **Testamentary Guardian** - named in the will of either a parent or spouse\* who is also the guardian of the ward (court leniency -tends not to limit only to spouse or parent).
- **Guardian ad Litem** - assigned to protect the rights of the person while waiting for a court proceedings (e.g. determine guardianship)

# Paperwork - Guardians

- Average cost -  $\geq$  \$3,000 (uncontested)
- Testamentary -  $\geq$  \$300
- Those who seek to be a guardian, but fall below the poverty line should contact the Office of Guardianship to get on the waiting list for the Guardianship Program where the fee is free or nominal 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

# Food For Thought- Guardians

- All guardianship in New Mexico –private or corporate- can go through the Office of Guardianship for information and for pointing them in the right direction. However, this office oversees Corporate Guardianships.\*
- Guardians are to be in the Best Interest of the ward.
- Guardians should ask the ward what his/her wishes are and try to grant those wishes in the most practical and reasonable way. Guardians have the final decision. ( Decision Justification form).



# Food For Thought

- ◎ Understand the law to protect clients' & others' right
- ◎ Knowing the law...less imaginary fears of “Liability”
- ◎ Speak with confidence. If you are going to get fired- let it be due to your integrity
- ◎ Check documents when surrogate decision makers are claiming they have the authority. Trust your instincts, common sense!

# Food For Thought

- Educate care-givers, family and team members- so that they are also 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- or at the expense of the client/individual

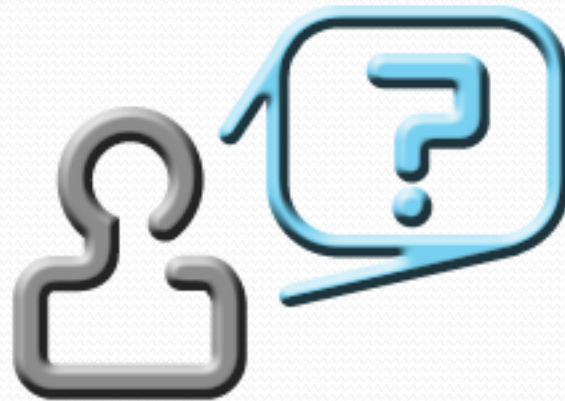
# Decisions, Decisions

- ⊙ Assume that individuals can make his/her own decisions unless incapacity has been determined by 2 professionals or the court.
- ⊙ Individuals and surrogates (POA, Guardians) should have full access to disclosure of medical information
- ⊙ Legally - Healthcare Decisions are made by the individual, guardian or surrogate...not by the **Inter-disciplinary Team** members, “the State” etc.,

# Decisions, Decisions

- Healthcare Decisions are often Value driven
- Recognize and respect the cultural differences
- Healthcare decisions can be revised at any time by the *authorized* decision maker (capacity)
- Quality of life should be at the forefront
- Individuals must be treated with dignity and respect...regardless!

So what do you do when  
you need a little help?



# Next Phase for introspection

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



- *Education and supports can help both the terminal patient, the family , IDT members and other support system*

And then, there are times  
when it seems that hope  
is not enough





# No Man is an Island...

- *Any man's death diminishes me, because I am involved in mankind; and therefore never send to know for whom the bell tolls; it tolls for thee...*

*John Donne* ~Meditation 17  
Devotions upon Emergent Occasions

# *Resources...*

*in conjunction to DDSD Regional Office*

- Local Champions -Continuum of Care
- TEASC & Special Needs Clinics
- HDR (Healthcare Decision Resources) Committee
- Aging & Disability Resource Center
- Ethics Committee-Hospital
- Ombudsman -Long-term Care, SNF/NF
- Hospice

# *The road ahead...*



- ◉ *Dying is a normal and natural process*
- ◉ *No need to fear it*
- ◉ *No matter the condition, we will all go through the same physiological process, but the experience will be unique for each of us*



Dying is a personal experience, not a medical  
problem  
(anonymous)

# *The road ahead...*

- *Most people had the terminal condition way before it was diagnosed*
- *Although most people equate pain with death, pain is an indicator of the condition or illness advancing, not the indicator of death*
- *This is time when the team should come to the aid of the individual*

# *The road ahead...*

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

Understand that it ain't easy being a healthcare decision maker...nor a Case Manager, Nurse, Service Coordinator, etc.

# *The road ahead...*

Work towards finding a good plan for carrying out the healthcare decisions... as a member or support to the team

Team members/Supports 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 care

**DOCUMENT, DOCUMENT, DOCUMENT**

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

- ⦿ 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, 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...*

- ⦿ Standardized EMS -DNR Form
- ⦿ Only form they will honor
- ⦿ Place it where it is conspicuous, freezer/bag, carry order w/you ( medical bracelet)
- **Some 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

# When its terminal

- This is a delicate topic and some cultures find it difficult to broach, but by discussing before hand with the individual, guardian, etc. you take the guess work out and keep the tender moments to have closure without the ugliness of meetings or scrambling to get things in place.
- Support Teams in getting everything in place, continue to communicate and update and document for peace of mind. So that you don't perseverate about "if only I had..."
- Quality of care until the last breath is taken

## *And when the individual has intellectual /developmental disabilities*

- Take pain seriously as early or warning signs may have been overlooked and the individual may not be able to communicate well what is bothering him
- Work towards making the individual comfortable and carrying out his/her wishes to the extent that they are known

# Safe passage -

- Check on 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 above
- What to do with the belongings (secure heirlooms or precious items)
- Let establishments and agencies know
- Once death certificate has been signed...

# *Crossing the Finish Line*

*Regardless...for most terminal patients,  
those around them at the time of passing...  
say it is was*

*Peaceful*

# *Grief & Bereavement*

- 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*

- Anticipatory Grief - caused by an impending or upcoming situation or expected loss
- Bereavement - grieving after a loved one's death (human or pet)

# *Movin' on*

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



# *Healing*

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

(Sharon O'Brien, about.com)

# *Healing* ~Some Suggestions:

- Learn to accept that your loss is real
- Make it OK to feel the pain...so you can ease the pain
- Adjust to working - knowing that this individual is no longer in your case or patient load
- Accept the fact that - our clients do impact our lives and vice versa

# *You are not alone*

- ◎ Get ready for Mortality Review - if Jackson
- ◎ Keep an open mind to feedback as this may not be the only time you go down this road.
- ◎ 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

# *You are not alone*

- ◎ Take good care of yourself...you have gone through a lot!!
- ◎ Talk about this experience with a confidante
- ◎ Be loving & forgiving ( bury the hatchet)
- ◎ Get good sleep
- ◎ Eat well & Exercise
- ◎ Take breaks during work

# *You are not alone*

- ⦿ Add laughter into and throughout your life
- ⦿ 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

Thank you