



# *Advocating for Peace of Mind*



## Continuum of Care Project

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# Know Thyself

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Examine your own philosophy on

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

# Know Thyself

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

# Get the paperwork in order & update as needed...Capacity required

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

# Capacity

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- 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

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- 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 professionals make an assessment- one of which must be the PCP
- If mental health or developmental disability, one of the health care professionals must have expertise in assessing functional impairment

# Paperwork...

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- **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...

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- ⦿ 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

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## “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

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

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- 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

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- ⊙ 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.]

# More Paperwork

Don't be confused

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## “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

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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

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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

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- 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

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- 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 who, what the Principal can spend his/her money on, etc.



# Paperwork - POA

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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.

# Surrogate Decision Makers

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- An individual, other than a patient's agent or guardian, authorized under the NM 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

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



# More on Surrogates

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- DDSD Form for stating 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
- Please contact Christine Wester, LBSW, MPA at the IAA/DRP Unit (see resources)

# Paperwork - Guardians

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- 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

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- Average cost -  $\geq$  \$3,200 (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

# Additional form for Consideration

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- *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

## Decision Consultation Form

DOH developed form

Refer to DDS  
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



# Decisions, Decisions

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- 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!

# Decisions, Decisions

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- ⊙ Assume that individuals can make his/her own decisions unless lack of capacity has been determined by the courts per 2 professionals
- ⊙ Individuals and surrogates (POA, Guardians) should have full access to disclosure of medical information
- ⊙ Legal Healthcare Decisions are made by the Individual , guardian or surrogate...**not by the Inter-disciplinary Team members**

# Next Phase for Advocacy

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- 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

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- ① Understand the law to protect clients' & others' right
- ① Knowing the law...less imaginary fears of "Liability"
- ① Speak with confidence, if you are going to get fired- let it be due to your integrity
- ① Check documents when surrogate decision makers are claiming they have the authority . Use common sense!

# Food For Thought

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- 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- and never at the expense of the client/individual!

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

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

# *The road ahead...*

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- ◉ *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*

# *The road ahead...*

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- *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...*

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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*

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- ⊙ 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*

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- ⊙ 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

# *The road ahead...*

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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**

# When its terminal

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- This is a delicate topic and some cultures find it difficult to broach, but by discussing before hand with your agent, executrix, 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.
- Once you do have everything in place, continue to communicate and update and document for peace of mind and your last thought won't be wasted on thinking about all of the “if only I had...”
- Quality of care until the last breath is taken

*And when the individual has intellectual  
/developmental disabilities*

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- 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

# *Crossing the Finish Line*

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

*Peaceful*

*Focus on the Person's Life*

# Safe passage -

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- 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)
- Once death certificate has been signed- establishments and agencies will need to be notified



# *Grief & Bereavement*

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- 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*

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

# *Movin' on*

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- 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

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

(Sharon O'Brien, about.com)

Some Suggestions:

- Learn to accept that your loss is real

# *Healing*

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- 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*

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- ◎ 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*

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- ◉ 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

Thank you

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