## "I got your back..."

With Aging comes healthcare decisions & the importance of getting things in place



Ingrid M. Nelson, MS
Continuum of Care Project
University of New Mexico

### **Disclosure for Learners**

- This will be handed out in their packet as well as the 1st slide before every presentation.
- You must sign in in the morning, attend the entire conference, and complete the evaluation forms to receive a Certificate of Successful Completion
- Please make sure that your email is legible on the sign in sheet
- There are no conflicts of interest for the planners or presenters of this activity
- The presenter will disclose any off-label use of medications verbally during their presentation
- There was no commercial support for this CNE activity
- Approval does not imply endorsement by ANCC or NMNA
- Lunch will be provided by Continuum of Care in this conference area
- To be respectful to presenters and others seated around you, please turn cell phones and pagers off or to vibrate mode and step outside if you need to take or make a call
- Bathrooms are located in main hallway near front door

## What you should get from this training/discussion:

- NM Uniform Healthcare Decisions Act and who has the right to make healthcare decisions
- Making Decisions quite a task
- Meetings and paperwork to support informed Decisions
- DNR when and where its a tough decision, but necessary choice for some
- Decision Consultation & Team Justification Forms
- Stay strong Teams as Advocacy is a driving force
- Quality of life should always be at the forefront
- Reviews & Group Discussions

## NM Uniform Healthcare Decisions Act

• "It aims at assisting individuals and the medical profession in better assuring a person's right to choose or reject a particular course of treatment."

• "This act consolidates various state laws dealing with all decisions about adult healthcare and health care powers of attorney. This act supersedes the Uniform Healthcare Consent Act and the Uniform Rights of the Terminally Ill Act."

## Determining factor...capacity

- Capacity refers to "an individual's ability to understand and appreciate the nature and consequences of proposed healthcare and to make and communicate an informed healthcare decision."
- For Advance Directives- the *individual* has to have capacity
- For Healthcare decisions- it is implied that the agent, guardian or surrogate has capacity



Who has the right to make Healthcare Decisions?

# Who has the right to make Healthcare Decisions

### I. Individual with Capacity



Remember that a non-adjudicated adult makes his/her own decisions starting at 18 years of age

If there is a question about the person's capacity, discuss with IDT and look into assessments

2 professionals credentialed to make this type
of an evaluation and who is familiar with I/DD

one of the 2 should be the PCP

## 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 initiate an Advance Directive
- No one can make an Advance directive for another person.

## Paperwork...

- 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 (Agent (POA), Surrogate 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 an Agent or Attorney –in-fact (POA). The Agent will make healthcare decisions for you. However, this form <u>does not</u> 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

## Advance Directive

- Oral or Written Request
- Placed in Medical record via PCP or medical professional
- While a person is of sound mind and body

• Usually way before a medical crisis has occurred – it is an "in the event" kind of form

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

- 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

## More Paperwork

"Power of Attorney"

(the form with this name on the top)

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

oHealthcare oFinance or business

### More Paperwork...

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 <u>must be notarized</u> in order for it to be a legal document. For Healthcare- witness & notary is recommended, but not required.

## 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)

15

## Paperwork...POA

•Powers of Attorney *can* start immediately but the Principal decides by indicating suchwhen completing the form (this option is often chosen when the Principal is in a serious or terminal condition).

## Paperwork - POA

The Principal should not complete this form under direst, 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.

## II. Agent, Attorney-in-fact or Health care Proxy

- Designation of Agent:
- I designate the following individual as my agent to make healthcare decisions for me...
- You can have alternate agent(s) if you revoke the 1<sup>st</sup> agent's authority or if the 1<sup>st</sup> agent is not willing, able or reasonably available

- Best to have a Primary agent, secondary, and so on...if you must
- Otherwise, decisions have to be made jointly-that is all good *if* the 2 or 3 people get along
- Family/Friends can act ugly under stress, when emotions run high, etc.: they can forget that they are suppose to be there for YOU

## III. Surrogates -Through the NM Uniform

Healthcare Decisions Act\*

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



## More on Surrogates

- 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 (consult with PCP)
- Please contact Christine Wester, LBSW,MPA at the IAA/DRP Unit (505) 841-5529

### IV. Guardians

● 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 (courts will determine to what extent/area)

Treatment\*

Temporary (60 days- critical situation)

Guardian ad Litem (interim until court decision)

<sup>\*</sup> Mental Health & Developmental Disabilities Code

### Guardians

(basing decisions, for the most part, on the Ward's wishes)

- Generally, they are responsible for maintaining and enhancing their Ward's quality of life by:
- Making sure that the Ward's food and clothing needs are met
- Making sure that the Ward is involved in recreational activities that he/she likes
- Making sure the Ward has good training and education
- Making sure the Ward stays healthy; Remembering that as guardians, they should be actively involved in making sound health care decisions (may include consenting/refusing medical treatment)...in alignment with the Ward's values.

## Paperwork - Medical

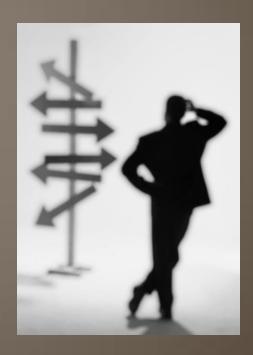
- These forms need to follow Waiver standards & guidelines, Nursing practices, etc. to assure that these documents are accurate, updated when there are changes, person-centered and accessible- that the documents are properly placed or stored and that all staff know where these documents are kept (so that they can get to them quickly).
- The forms should also be <u>reviewed with regularity</u> to ascertain that they are in order.
- MARs
  Health Care Plans
  M.E.R.P.

## Advocacy - Food For Thought

- OUnderstand and know the policies, laws, standards, etc. to protect clients' & others' rights...less imaginary fears of "Liability"
- Respect the decisions follow procedures/law, if you are going to get dinged- let it be for your integrity (don't fall into the trap of thinking your way is the right and only way)
- Follow through with healthcare decisions or if you need clarification request it and don't make assumptions
- Check documents when surrogate decision makers are claiming they have the authority. Use common sense!
- Tap into available resources- Ombudsman, TEASC, etc. 2

## Decisions, Decisions

Not an easy task



## Advocacy - Food For Thought

- Educate care-givers, family and team membersso 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 permitsand never at the expense of the client/individual!

## 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!

## Advocacy...

Healthcare professionals should be invited to IDT meetings so that medical complications can be explained (via phone, video conferencing or provide their 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

## Despite all your (good) efforts...

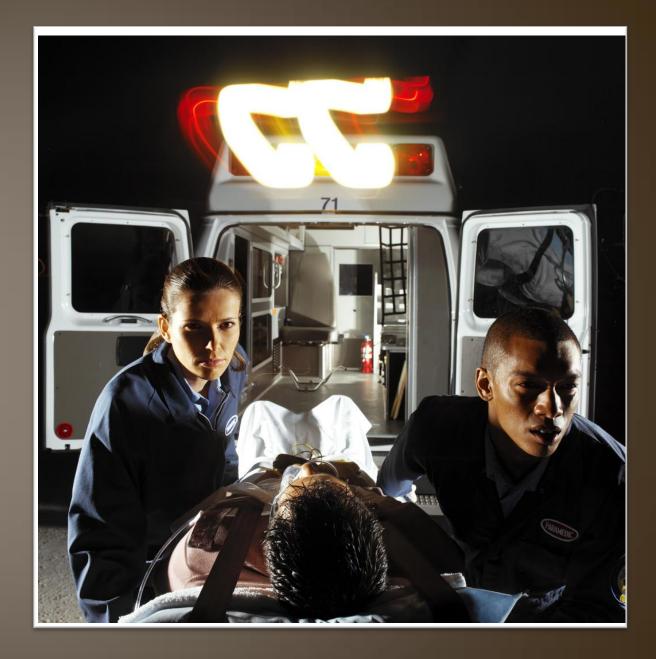
- Chances are there will come a point when a treatment choice is going to be refused, when treatment can not improve the condition, be futile and/or when it is decided that the patient should not endure any more(just existing and not living) no longer quality of life.
- Let him leave with dignity
- Do Not Resuscitate (DNR)
- Do Not Intubate (DNI)
- Do Not Attempt Resuscitation (DNAR)
- Allow Natural Death (AND)



## DNR

Just one of many tough healthcare decisions that one might have to make





## In New Mexico

- Standardized EMS -DNR Form
- Only form they will honor
- Transporting to and from Residence, Group homes, Assisted Living, etc.
- Place it where it is conspicuous, freezer/bag, carry order w/you (medical bracelet) Copies are OK.
- Most hospitals (Long-term care, medical facilities, SNF/NF, Hospice, etc.) will only honor 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) or initiated at the hospital.
- All DNR orders must be signed by a physician
- This may be a bitter pill for some staff/teams

## Advocacy...

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 <u>Quality of care</u> in support of the individual's <u>Quality of life</u>

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



Putting the Decisions on Paper

# FORMS

the love-hate relationship we have with them

- Documenting is a way to capture the team process and state what the decision or determination is.
- Caveat <sup>⊕</sup> Because it is on paper, does not mean it will not be questioned.
  - Still ...it is better to have *a* document and have the Authorities question <u>some</u> things, then to have *no* document for them to question <u>everything!</u>



The theme or thread should hold true throughout with all forms or processes: The reason for this decision or intervention should be in line with the Individual's Quality of life.

# Get the necessary paperwork and keep them filed and in order

- ✓ Ascertain that the decision maker falls in one of the above categories (This is especially true, for example, when an individual was a minor upon entering into the Waiver system (your case load) and you were used to his parents making the decisions, but now he is 18/an adult).
- ✓ Make sure Contact information is accurate and current and that he/she is accessible including phone numbers and best time to call or alternate numbers and designee

## Get the necessary paperwork and keep them filed and in order

- ✓ Read the legal documents (thoroughly) confirming that the person named has the authority to make healthcare decisions
- ✓ Check that the document is bona fide and current
- ✓ Make a copy of the legal documents
- ✓ Assure that necessary Waiver documents coincide with this information & are attached



DCF The main form for documenting
Healthcare Decisions- why this form?

### This is what normally happens...

- Medical situation occurs, the medical professional explains the condition to the patient and/or Decision maker laying out the prognosis including the "what could go wrong" the risks, benefits, alternatives/options. Or there's a Doctor's Order.
- Decision maker mulls it over and/or talks with trusty family advisors/friends and (hopefully) makes an informed decision
- Both the medical professional and the Decision maker are operating on the premise that Knowledge is power
- Medical team carries out the decision or directive- no document is needed (once the person is identified as the decision maker) other than release forms, disclosure form...
- Rarely is the decision maker questioned unless there is real concern about lucidity/capacity or neglect- honor system

#### DD Waiver... is a different animal

- With the DD Waiver there are more checks, balances, rechecks and questions...under the microscope= normalcy within this realm to protect the individual, team, etc.
- The very nature of the IDT is layered enough for outside entities to want to see if all the steps have been carried out- if all the documents are in order...ACOUNTABILITY
- Documents should verify that the team has convened, decisions were made, support by IDT & it's personcentered!
- No conflict of interest, no abuse, neglect or exploitation
- Show it, Prove it! -Vindication and Justification is the thrustwhich is understood as Advocating and protecting the rights
- Assumption! that all is in order only when there is proof

### Decision Consultation Form (DCF) [DDSD Policy on Team Decision Documentation]



- Used to document medical/health related or clinical decisions whether agreeing or disagreeing
- Must be used each and every time when disagreeing with or deferring from a medical recommendation
- Must be used when deferring from aspiration or Comprehensive Aspiration Risk Management Plan (CARMP) recommendation(s)

### Decision Consultation Form (DCF) [DDSD Policy on Team Decision Documentation]

- To guide and document team discussion in a manner that promotes informed decisions
- \* A means of letting the IDT members know what the issue is and the final decision made regarding a recommendation
- Help teams to get into a rhythm/pattern of discussing, educating, bringing in the necessary experts, supporting the decision maker in arriving at an *informed decision*, communicating that choice and advocating for the Individual's to have a quality of life
  - best interest



### Decision Consultation Form (DCF) [DDSD Policy on Team Decision Documentation]

Once a decision has been made by the healthcare decision maker, the Practitioner/consultant who made the recommendation is notified then the Case Manager files this form along with the report that contains the recommendation.

Relevant support plans should be revised accordingly-especially the Health and Safety Action Plan page of the ISP, healthcare plans, MERP, Therap, etc.

Its about making sure the patient has exercised his/her rights



Advocacy, policies standards provide guidance and are lawful- statute based...and all is documented

- o Remember-Although "order" is used, a doctor *really* gives "recommendations"
- By law, an adult has the right to: Follow or refuse any part or all of a medical recommendation
- Ask for a 2<sup>nd</sup> opinion
- Defer or disagree with some or all of the doctor's orders
- Deferring or disagreeing does not necessarily mean one lacks capacity
- Exercise a method that indicates when a decision maker has made an <u>informed decision & that IDT is aware</u>



# TJF The other main decision form

### Team Justification Form (TJF) [DDSD Policy on Team Decision Documentation]

Used when the Team <u>disagrees</u> with a <u>Non-medical</u> Recommendation

- Must be used each and every time the team disagrees with an Employment recommendation
- \* In conjunction to above, IDT must develop goals and state what will be the more preferable alternative to employment (e.g. volunteering)
- For responding to Community Practice
   Review (CPR) recommendations or any other

### Team Justification Form (TJF) [DDSD Policy on Team Decision Documentation]

- Indicates that the team, through a facilitated process, has given due consideration to a recommendation and as a result, has made a determination.
- The determination is properly documented on the TJF which includes the pertinent discussion points therefore justifying the determination
- Use for teams that have determined that a Non-Medical recommendation shall not be implemented

#### For both forms

[DDSD Policy on Team Decision Documentation]

These forms are appropriate for all inter-disciplinary teams who support adults (individuals 21 or older who are no longer eligible for EPSDT benefits) on the DD Waiver

#### For both forms

Although the Case Manager is the one who generates the forms, and helps facilitate, it is through the team collaboration that these forms are made complete with all the elements to reflect what has lead up to the final decision.

• The member who has been most involved with the situation should be a fulcrum: ascertaining that the information is accurate, sequential and so forth.



#### For both Forms

- It has been suggested that all members are given the form ahead of time to become familiar and do some "prep" work before the actual meeting occurs to discuss the situation or particulars
- This can encourage IDT member's full participation, their careful thought to the issue at hand, research, inviting the experts and resources to attend the meeting. It can move the discussion and team process to efficacy and productivity (as opposed to the mundane, un-involved, unaware, one-way meeting).

O Keep in mind that each culture may approach healthcare issues differently

Find the best way to broach the topics

Support and advocate- it is crucial

Be aware of decision, participate in the meeting well enough to be able to explain or defend it



We should ask ourselves questions to make sure we have covered the bases or have considered the pros and cons

• Questions are a necessary feature of Advocacy – don't dread them, anticipate them

Reviewing Entities are *supposed* to ask questions and Teams are supposed to have answers: especially since the Team process involves properly examining the situation (first hand), proposing questions, and exploring solutions— final decision

## Getting Things in Order – a piece of Advocacy

- Meeting to discuss/know course of action
- Person-centered and specific
- ISP with some meat/substance in it SIS done?
- Plans in order: leave no stone unturned
- Decision Consultation, Team Justification, Surrogate Forms
- May need to reconvene or conference call
- RORI for those who need just an extra wake up call
  - Delineate who does what (i.e. IDT + Hospice team); make sure all necessary documents are accessible (e.g. at home, Day), current, accepted in hospital, etc.

### Nevertheless, when there's a death, You are not alone

- Get ready for the 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)
- Ohospice can be helpful with Grief counseling for the family and staff...utilize this service



O Don't work in Fear!!!

Stop 2<sup>nd</sup> guessing yourself *all* the time especially in cases involving JCMs - difference between precaution vs phobia

Be confident with utilizing the team's professional judgment! Confident in supporting the Individual, and/or Decision Maker & the team as a whole!

### Wrap up

There are 4 main legal decision makers (capacity) Use Decision Consultation Form for Medical, healthcare, therapeutic or clinical recommendations

Healthcare decision maker makes → informed decision \*\* IDT does not make healthcare decisions for the Individual

Healthcare professional/source who made recommendation is notified of decision, CM files DCF w/report

Update relevant documents

# Wrap up Team Justification Form is for non-medical recommendations

IDT discusses and makes Determination

CM informs entity that made recommendation & files TJF w/report

Update relevant documents

Review In a Nutshell

# Thank you