



*Advocating
for
Peace of Mind*



**Continuum of
Care Project**

Ingrid M. Nelson, MS

University of New Mexico
Health Sciences Center
Department of Pediatrics



Know Thyself

2

Examine your own philosophy on

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

Know Thyself

3

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

4

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

Capacity

5

- 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

6

- 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...

7

- **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...

8

- 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

9

“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

Psychiatric Advance Directive (PAD)

10

- AD-Advance Directive for Mental Health Treatment*
- Similar to Healthcare Advance Directives and should be honored similarly. There are some differences:
- Documents must be signed, dated and witnessed
- Create AD or complete AD when you are WELL, if not the Court could decide not to follow your wishes
- WRAP or Wellness Recovery Action Plan can be included and if signed, dated and witnessed, can be used as an AD
- *NM Mental Health Care Treatment Decisions Act*

Disability Rights
of New Mexico

(505) 256-3100

National Alliance
on Mental Illness
(NAMI)—
Albuquerque

(505) 256-0288

OptumHealth NM
1-866 -660-7185



**General information about AD
forms and/or creating on**

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

12

- 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

13

- 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

14

- *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

More Paperwork

Don't be confused

15

“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:

- o Healthcare
- o Finance or business

More Paperwork...

Don't be confused

16

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

17

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

18

- 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

19

- **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

20

The Principal should not complete this form under
dirst, 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.

Safeguards



- When a person lacks capacity, she/he is vulnerable and can be the target of abuse, neglect or exploitation
- Surrogates or guardians are put in place to be responsible for assuring that the person lacking capacity is “protected” and is in a healthy and safe environment

Paperwork - Guardians

22

- 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

23

- **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

24

- **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). Registered at court.
- **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 - ≥ \$3,400 (uncontested)
- Testamentary - ≥ \$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
- Contact Jannel M. Vigil, CIRS - Intake Coordinator
DDPC Office of Guardianship (505) 841-4549
625 Silver Avenue, SW Suite 100
Albuquerque, New Mexico 87102 or www.nmddpc.com

Surrogate Decision Makers

26

- 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

27

- 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 individual's PCP)
- To receive info: Please contact Lisa Storti, Office of Constituent Supports (505) 476-8972 or (Deputized) Ingrid Nelson/CoC (505) 925-2374

Next Phase for Advocacy

29

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



And when the individual has intellectual /developmental disabilities

30

- 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

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

31

- 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*

In New Mexico



- Standardized EMS -DNR Form (Only form they will honor)
- Statutory Form for New Mexico
- 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.
 - * NM Medical Orders for Scope of Treatment (M.O.S.T)

Decisions, Decisions

33

- ◉ 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 w/capacity...
Not by the Inter-disciplinary Team members

Decision Consultation Form

DOH developed form

Refer to DDSD
Regional Office for
questions

DOH Web * ACT N.M.

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
Healthcare Decision
maker

- 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

35



- Healthcare Decisions are often Value driven-along with beliefs, preferences, habits, attitudes
- 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!

Values Based

36

- Gently initiate discussions which allows the Individual to share his/her perspectives and values
- The Value's History Form, for example, 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. However, do ask questions when seeking to genuinely understand

Let's Talk

37

SCENARIOS

Advocacy - Food For Thought

38

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

- 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
- Educate care-givers, family and team members- so that they are also in the best interest of the individual

Food For Thought

39

- 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!
- Check documents when surrogate decision makers are claiming they have the authority . Use common sense!

The road ahead...

40

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

When its terminal

41

- This is a delicate topic and some cultures find it difficult to broach, but by discussing before hand with the surrogate, guardian, agent- 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

The road ahead...

42

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

*You are not alone: Resources...
in conjunction to DDSD Regional Office*

43

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

You are here for a reason

44

- 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

You are here for a reason

45

- Talk about this experience with a confidant -this is when other IDT members or colleagues can be a support
- 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

46