

*“...until the last breath ...*

*Addressing End of Life issues in I/DD”*



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# Topics and Discussions

- ✿ Making Plans while things are going well
- ✿ Being Prepared
- ✿ Decision Making- life's philosophy
- ✿ Working with medical team and IDT
- ✿ Scenarios



# *Topics and Discussions*

- ✿ Terminal Conditions, phases & preparation
- ✿ Complications in Terminal Individuals w/Intellectual Disabilities
- ✿ Comfort Measures



# *Topics and Discussions*

- ✿ Having the Conversation
- ✿ Supports, Care-giving, Advocacy
- ✿ Grieving & Bereavement
- ✿ Movin' On



# *Food for Thought*

*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)



# *Being Comfortable around those who are dying*

- ✿ Why are most people uncomfortable or hesitant to be around those who are terminal or dying?



# *Being Comfortable around those who are dying*

- ✿ Each person must ask him/herself why that is...as the answer lies within.
- ✿ A time for Introspection





# *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.



# *Being Comfortable around those who are dying*

- ✿ Education and supports can help both the terminal patient and those who are part of the family or support system
- ✿ Provides an opportunity to delight and share moments with the terminal patient and then find comfort in the memories about the life that person



# 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 or community programs*

- Local medical Consultants -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



# Get Paperwork in Order

- ✿ Five Wishes
- ✿ Advance Directives
- ✿ Guardianship and Healthcare decisions
- ✿ Power of Attorney
- ✿ Surrogate Decision Makers when decision makers are not accessible



# Paperwork...Advance Directive

- **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
- **Living Wills** were grandfathered in as a type of **Advance Directive** back in the 90s



# Advance Directive

- ❁ Oral or Written Request
- ❁ Placed in Medical record - via PCP or medical professional; kept in a safe place at home
- ❁ While a person is of sound mind and body
- ❁ *Usually* initiated before a medical crisis has occurred - it is an “in the event” kind of form ( 5 Wishes for example)
- ❁ You sign one when you go to the Emergency Room or admitted to a Hospital



# Paperwork...Advance Directive

- A person has to have capacity ( i.e. abstract or creative thinking, ability to think ahead, think outside of the box , etc.,) in order to initiate an Advance Directive
- A “What if...” preparatory approach to ones healthcare. No incident or situation is necessarily needed to prompt one to fill this form: *Proactive*





# 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



# Additional form for Consideration

- ✿ *My Wishes* is based on the Five Wishes
- ✿ For Children/Minors/Wards
- ✿ 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

## “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.

Simply: POA is a legal statement or document that authorizes one to act for another



# 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 must be notarized 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.,)



# Paperwork...POA

- However, 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).



# Surrogates -Through the NM Uniform Healthcare Decisions Act\*

## Hierarchy of Surrogates

- 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 on this form Please contact Lisa Storti, DDSD Office of Constituent Affairs(505) 476-8972 or Ingrid Nelson/CoC (505) 925-2374



# 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)

\* *Mental Health & Developmental Disabilities Code*



# Guardians



Sometimes guardians may need to go out of town, take a break, etc.

So...a guardian may delegate to another qualified person -via POA -any or all of the powers/duties the guardian possesses for a period of time up to 6 months (Probate Code Section 45-5-104)

*\* This can be renewed for another 6 months...*

# Now that we know who can make healthcare decisions...

- ✿ Let's move along with activating Healthcare
- ✿ Lets properly utilize the medical community to get guidance on a good course or plan
- ✿ Concepts to keep in mind: Doctors & medical professionals don't have all the answers, nor do you. So, make this about co-creating to develop or modify a healthy plan



# Now that we know who can make healthcare decisions...

- ✿ Med professionals base their recommendations on their level of expertise, observations, tests, lab work, etc. and information *you* supply
- ✿ Make appointments count – you should know why this visit was made and what you hope to accomplish from this doctors visit, considering recommendations, meds,& so on- write concerns down and check them off after discussing with the med professional.

# Red Flags

Note when even the slightest condition changes-check with nurse as to when indicated care/intervention is needed-

- \* Weight changes
- \* Decline in function
- \* Haven't had a seizure in years, but all of a sudden is having them
- \* Making sounds, grimacing – which they did not do before- which could be conveyed as pain
- \* Appetite diminishes
- \* Bowel movement (diarrhea or constipation)
- \* Seems disinterested in the things he/she used to like
- \* Energy level is not “normal” for that person
- \* Behavioral and/or mood swings
- \* Temperature ↑↓



# DD Waiver- Having a Plan with the key players

- ✿ Nurse is your first line of medical advocacy (they develop the healthcare plan, MERP, check MARS, Board of Nursing, Waiver Standards, Agency policy, etc.)
- ✿ PCP is the Hub –coordination of medical services within the community and referral to specialists
- ✿ Specialists to address specific concerns or conditions- they should work in tandem with PCP & nurse



# Having a Plan with the key players



- ✿ Direct Support Professionals & other day/residential Care givers ( i.e. Family Living, family members)– usually spends the most time with the individual. When they are sharp & invested- they know the client’s physical mannerisms, their quirks, their gestures...they have a wealth of information from their own interactions and observation of & with the individual

- ✿ They must be involved when gathering data and observations and be integral in the coordination of healthcare services- *Agency to develop Dr. Visit Face sheet*

# Having a Plan with the key players

- ❁ Therapists –a specialized service with specific goals for the development of a plan in accordance with the ISP (scale, assessments and findings); adjustments made when conditions change– don't just change the date of the report!

- ❁ Case Manager and Service Coordinators to make sure there is documentation of all that is done, standards are followed, correct forms are used to pull it all together-keeping a dynamic tracking system





# Having a Plan with the key players



- \* *An actively involved and devoted healthcare decision maker- who sees the team as a support & resource; who has a solid rapport with the members; communicates openly and regularly with the team (including updates on decisions); and is readily available to meet, decide, etc.*
- \* The above players should be communicating and /or interfacing with each other regularly and assertively and not just in response to a crisis or emergency. Nor should they act as if it is an inconvenience when they are contacted.

# Getting things in Order

- ✿ Develop a professional and supportive rapport with the decision maker(s)
- ✿ Serious medical conditions and terminal cases can have emotions running high...so try to establish a connection long before a crisis reaches its crescendo



# Documentation: Decision Consultation Form

Empowering & supportive document used when a difficult medical decision is made; form should be completed entirely with pertinent information - outlining discussion, options and the informed healthcare decision

Remember:

*Decision Consultation Form* for healthcare issues; and *Team Justification Form* for non-healthcare issues



## Documentation: Decision Consultation Form

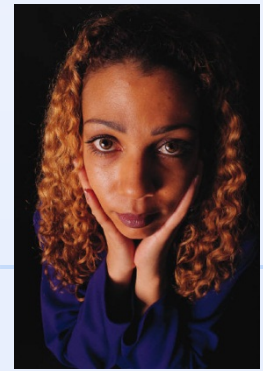
- ⌘ Case Manager generates, completes, submits & appropriately files this form
- ⌘ Assistance: from nurse on medical component or IDT member with the most information
- ⌘ Captures key points of meeting(s) whether formal or informal -indicating that condition was discussed, options were considered and an informed decision was made by the legal healthcare decision maker (e.g. Guardian, non-adjudicated Adult, POA, surrogate)
- ⌘ Stand alone document



# Decisions, Decisions

- ◉ 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**

# 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!

# When its terminal

- \* This is a very delicate topic and some societies 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..."
- \* Assure needs are being addressed by having the "Conversation"

# *Peace of Mind*



Having the “Conversation”

Tackling fears, wishes, treatment, finding out what makes the patient happy

Asking what s/he wants; keeping caregivers and loved ones in the loop

Knowledge is power- patient/decision-makers should know options and rights



# Specialized supports for End of Life

## Hospice

Palliative vs curative care

Condition with estimate of @ 6months (can be extended)

Hospice Team of physician, nurse, home health aide, chaplain, social worker and (often) volunteers

Bereavement

Grief supports to family or care givers months after patient has passed away



# 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 –
- ✿ Plans in order: leave no stone unturned
- ✿ Decision Consultation, Team Justification, Surrogate Forms
- ✿ May need to reconvene or conference 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.

# *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



# *This may be in the mix*

- ◉ 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



# Paperwork in Order...

- ✿ NM Medical Orders for Scope of Treatment (NM MOST) form
- ✿ So that the legal documents are one less thing to worry about
- ✿ Allows you to support the decision makers
- ✿ More time to spend with the person



# *Food for Thought*



- ✿ *Stages and what is typical when there is a terminal condition*

# *Comfort Measures*

- ✿ 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



# Comfort Measures

- ✿ Make the room and the environment comfortable
- ✿ Instill as many personal amenities for the patient throughout this process
- ✿ Think peace and tranquility- make it so - as often as humanly possible.
- ✿ Carrying out his/her wishes to the extent that these wishes are known



# *Advice for Care Givers*



- ✿ *Relax and Take Breaks*
- ✿ *Get medical check-ups*
- ✿ *Attend or help create a caregiver Support Group*
- ✿ *Know when it is time to pass the baton - to secure your relationship*

# *Advice for Care Givers*

- ✿ *Accept your own Limits*
- ✿ *Schedule and Organize*
- ✿ *Make time for yourself*
- ✿ *Stay Healthy -exercise, eat a balanced diet, get rest*



# *The road ahead...*

## *Loss of appetite and energy*

*Tendency- to want them to eat because having an appetite means they are getting better*

*Consider - Trust that the body has wisdom -trying to preserve energy or prepare for the next phase-don't be swayed by projections. Finger foods*

# *The road ahead...*

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## *Lack of Fluids*

*Tendency- to want them to drink when the body is starting to slow down and fluids can cause swelling and discomfort*

*Consider - Responding to the needs of the body as it has to go through this process- ice chips, lemon swabs, etc*

# *The road ahead...*

*Person becoming spiritual and turning introspective*

*Tendency- to think this is just a phase, especially when this person was not devout before*

*Consider - Listening and providing Spiritual supports and resources*

# *The road ahead...*

## *Pain Management*

*Tendency- to want them to stick it out- strengths comes from fighting this illness; addiction may occur with the pain medicine*

*Consider - Comfort and Pain control may allow the person to relax, let go and pass on*

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

- ✿ Watch for changes or new pattern in eating, breathing, sleeping, behaviors, etc.
- ✿ Try not to fall into the trap of seeing complaints as trivial
- ✿ Assure that the individual has a comprehensive screening at least annually and that concerns are addressed



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

- ✿ 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





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

- ✿ Vocalizing, rubbing the affected area, self-imbibed behavior such as rocking, grimacing, withdrawal, etc. may be signs of discomfort and pain
- ✿ Take nothing for granted. When in doubt ...discuss and figure it out



# *The road ahead...*

## *Death Talk*

*Tendency- to wonder if he really knows he is dying, is there fear and why is he talking about seeing deceased relatives*

*Consider - Listening, allowing him to work out his fears, use resources to explain this process, letting go and letting flow, reminiscing is helpful*

# *The road ahead...*

*Apnea, stillness, hearing or agitation*

*Tendency- breathing pattern changes, laying still w/no response, but hearing is the last sense to go*

*Consider - Pattern will change and most are not in a coma, but be careful of what you say as his hearing is continuously in-tuned*

# *Crossing the Finish Line*

- \* Knowing when it is time - what is needed for the patient to feel peace*
- \* Some wait for a person or condition for closure; desire to reconcile*
- \* Some need to be assured that all is in order and everything will be fine*

# *Crossing the Finish Line*

- \* Some keep holding on ... Listen for unfinished business or awaiting a date as this may be what is needed to let go (e.g. dying after anniversary)*
- \* Awaiting permission to move on*
- \* (especially if the person was the family rock or manger)*
- \* Others check out on-demand*

# *Crossing the Finish Line*

*Regardless, of how one passes away, that last breath is...*

*Peaceful*



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

# *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 (or pet's) death*



# Support

- ✿ *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*



# Support

- ❁ *Listening and letting the bereaved talk about the loss and about his feelings*
- ❁ *Offer practical support such as shopping, looking after the pets,*
- ❁ *Watch for signs of severity or if symptoms don't fade*
- ❁ *Provide on-going support for the months ahead* ([helpguide.org](http://helpguide.org))



# Support

*However, grieving may move to a whole new realm whereby the person becomes depressed, suicidal, etc.*

*At that point, professional interventions most often will be required*



# *Grieving and Healing*

- ✿ *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*



# *Grieving and Healing*

- \* *Make it OK to feel the pain*
- \* *Adjust to living without the deceased - you were with him/her for a reason - There are no accidents!*
- \* *Try not to get stuck with how the person died...the last breath is a release/relief...peace*
- \* *Have a plan for moving forward*

# *Grieving & Healing*

- \* Stop thinking about “the death” - that was just one moment in the person’s entire life*
- \* Remember the pleasant times with the person - no time for blame or coulda, shouda...*
- \* Let your life reflect -from now on- how wonderful it was for this person to be in your life (& vice versa)*

# Grieving & Healing

- \* *Find a safe place in your heart for your loved one, client, etc. and allow yourself to move on*
- \* *Share your experience with others through grief seminars and counseling - you will see that you are not and will never be alone!*





*What to do with the  
love that you feel?*



*Share it: Loving and Caring  
People will always find ways to  
love and care for  
others...cherish the memories of  
those who have passed away  
and remember what an honor  
it was/is to be in one's life.*

*Everything in its season  
Think Love...Pass it Forward*

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*Thank you*

