



Supporting Someone with I/DD in the Last Season of Their Life

Ruth Benjamin RN, GERO-BC,
CRRN, CDDN, CPHN

RN Consultant



Section 1: Resources for family members walking through the last season of life with a loved one with I/DD



Tips for Families Making Medical Decisions

Be

Be sure to include a circle of support for everyone involved.

Involve

Involve your loved one in the decision making whenever possible.

Don't be

Don't be afraid to ask questions of trusted physicians, nurses, and other medical personnel, that knowledge will help you to make informed decisions you can feel good about.

Be

Be sure the medical language and terminology being used to discuss the changes in your loved one's medical condition can be understood by you and your loved one (if involved).

Tips for Families Making Medical Decisions (continued)



Use

Use other means of communication when needed i.e. pictures, sign language, interpreter.



Be

Be sure a new diagnosis or medical concern is explained so that both you and your loved one can understand the changes, as well as the decisions needing to be made related to these changes.



Take

Take time to think about the information you have received (don't feel pushed or rushed into making medical decisions).



Stop and think about

Stop and think about what it is your loved one might want if they were making these decisions for themselves.

Tips for Families Making Medical Decisions

Continued

Have you ever had a conversation with your loved one as to what is important to them (would your loved one want to go back and forth to the hospital on a frequent basis, want a g-tube if they could no longer eat by mouth, endure medical treatments to help sustain their life)?

- Be sure your decisions are person centered (how does your loved one respond to medical interventions, hospitalizations, is your loved one fearful of medical procedures, what are their general fears)?
- What is important to you and your loved one when considering quality of life versus quantity of years lived (neither is wrong, but often different to different people).
- Involve palliative care early on to help provide both knowledge and emotional support for both you and your loved one.



Knowledge is Power

Terms and Definitions for Family Members to Understand

➤ Capacity Assessment:

- A capacity assessment refers to the assessment of a person's psychological/cognitive abilities to make rational and informed decisions.

➤ New York's Family Health Care Decisions Act:

- New York's family Health Care Decision Act allows for family members or close friends to make health care decisions for people who are unable to do so themselves, if there is not a health care proxy. **(We will talk more about this later in the presentation).**

➤ Consent:

- Permission for something to happen or a consent/agreement between all involved parties.



Knowledge is Power

Terms and Definitions for Family Members to Understand

➤ Informed Consent:

• Informed consent is obtained for “professional medical treatment.” The term “professional medical treatment” is defined as “A medical, dental, surgical or diagnostic intervention or procedure in which a general anesthetic is used, or which involves a significant invasion of bodily integrity requiring an incision or producing substantial pain, discomfort, debilitation or having a significant recovery period, or any professional diagnosis or treatment to which informed consent is required by law.” It should be noted that informed consent is not required for medical treatment which does not meet this definition (generally considered to be either routine or emergency treatment)

www.opwdd.ny.gov

➤ Health Care Proxy:

• The person does not need to have the capability of making and understanding all medical care decisions for himself or herself in order to be able to make a health care proxy. A person simply has to understand that he or she is giving another person (the health care agent) the authority to make medical care decisions on his or her behalf if and when he or she is not capable of making these decisions. The person appoints someone they love and trust to legally make these healthcare decisions on their behalf when they are no longer capable of making and executing health care decisions as stated in the proxy. www.opwdd.ny.gov



Knowledge is Power

Terms and Definitions for Family Members to Understand

➤ **Surrogate Decision-Making Committee:**

- In NYS, the SDMC committee is an alternative to the court system for obtaining consent for medical treatments when a patient lacks decision making capacity and has no other authorized surrogate.



Knowledge is Power

Terms and Definitions for Family Members to Understand



LST:

- Life Sustaining Treatment is any treatment that will potentially save or prolong a person's life such as cardiopulmonary resuscitation, ventilation, g-tube, or dialysis. A person with capacity, a person who has guardianship for someone, a HCP, or a person who falls under the New York's Family Health Care Decisions Act to make decisions for someone has the right to decline LST
- for themselves or their loved while they will need to complete the appropriate process when necessary. (6-step process)

Palliative Care:

- "Palliative Care is specialized medical care for people living with a serious illness". (i.e. cancer, heart failure, end stage kidney failure) People in palliative care may receive medical care for their symptoms along with treatment intended to cure their illness. Palliative care is meant to enhance a person's life during serious illness by focusing on person centered care that also involves their family. Palliative care can be provided in a number of locations and involves care by a multidisciplinary team.

- **Quotes Cited from National Institute on Aging**

Knowledge is Power

Terms and Definitions for Family Members to Understand



Hospice Care/Comfort Care:

- Hospice Care or Comfort Care (words often used interchangeably) is specialized medical care that falls under palliative care and “focuses on comfort and quality of life of a person with a serious illness who is approaching the end of life.” Attempts to cure the serious illness are now stopped. Hospice is provided for a person with a terminal illness when a physician feels the person has 6 months or less to live when their illness is allowed to run its natural course. **Quotes Cited from National Institute on Aging**

Artificial nutrition/hydration:

- A form of medical treatment that allows a person to continue to receive nutrition and hydration when they are no longer able to eat or drink by mouth.
 - IV nutrition-nutrients get delivered through a liquid solution through an IV line, a PICC line or port directly into the bloodstream
 - A gastrostomy tube (G-tube) is inserted into the stomach providing the ability to allow for nutrition to go directly into the stomach.
 - A gastrojejunostomy (J-tube) is inserted into the stomach, through the stomach and into the small intestine.

Knowledge is Power Terms and Definitions for Family Members to Understand

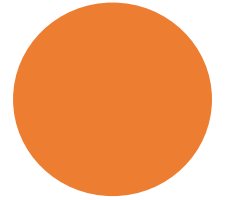
MHLS

- The Mental Hygiene Legal Service (MHLS) provides legal services, advice and assistance to individuals receiving care in certified settings. With respect to health care decision making, the Mental Hygiene Legal Service must receive notice of decisions by legally authorized surrogates who provide consent to withhold or withdraw life sustaining treatment for residents who lack capacity living in or transferred from facilities operated or licensed by OPWDD. Such facilities include developmental centers, intermediate care facilities (ICFs), and Individualized Residential Alternatives (IRAs).



Health Care Proxy

- Health Care Proxy paperwork can be implemented for a person supported with intellectual/developmental disabilities under the following circumstances:
- The person has someone they love and trust who is actively involved in their life to be their HCP.
- The person has had a recent capacity assessment indicating they have the capacity to choose an HCP to make their medical decisions for them when they can no longer make their own medical decisions.
- The paperwork for an HCP is completed between the person supported and their medical providers.
- The paperwork is signed by the physician, person for which the document is for, and a witness who is someone that is not associated with the organization in which they reside (the witness should not be the HCA, staff, or the RN from the persons residence).
- It is not suggested that a person with a guardian complete paperwork for an HCP as the guardian always supersedes an HCP and this can create conflict.



MOLST: Medical Orders for Medical Orders for Life-Sustaining Treatment

Legal Requirements For People with Developmental Disabilities

Steps in Completing the 6-step Process on an Outpatient Basis:

- The 6-step process must be initiated and completed by a physician with the family.
- For the 6-step process to be initiated the person must meet criteria in both 4a and 4b of the process.
- A capacity evaluation (see definition above) must be completed for the person by a licensed psychologist who has a minimum of 3 years' experience working with people who have in intellectual/ developmental disabilities.
- A concurring physician must also agree and sign the 6-step process.

➤ Steps in Completing the 6-step Process on an Outpatient Basis:

+

•

○



Both physicians must provide supporting documentation as to why providing LST would be an extraordinary burden for the person.



Upon completion, the documents for the 6-step process will be submitted to MHLS or the DDSO as well as the CEO of the organization for their review.



A representative from MHLS or the DDSO will visit the person prior to make their determination of objection or no objection (must be completed within 48 hours).

+
•
○

Steps in Completing the 6-step Process on an Outpatient Basis:

- The CEO of the organization will review the 6-step process and provided medical documentation and may visit the person prior to making a determination of objection or no objection.
- The letters of determination, capacity assessment, and 6-step process will be provided to MHLS, agency, and sent to the person's residence.
- After a determination of no objection there is a 48-hour waiting period which allows for any possible change in decision by either party.

Steps in Completing the 6-step Process on an Outpatient Basis

- The actual pink MOLST form will be completed by the physician and involved party.
- Once the MOLST is completed it should be made readily available for emergency personnel, a copy should go with the person when leaving their residence and should accompany the person to the hospital.



Steps to Complete the 6-step Process During Hospitalization

- The family and physicians caring for the person supported make a determination together to withhold or withdraw LST.
- The SW will contact the agency representative regarding the decision for withholding or withdrawing LST.
- The agency representative informs the appropriate colleagues
- Upon receipt of the 6-step process, capacity assessment, and supporting medical documentation the agency representative will provide such documents and any additional medical information to the agency CEO for review (within 48 hours)





Steps to Complete the 6-Step Process During Hospitalization (continued)

- The CEO makes a written determination of objection or no objection and submits to appropriate parties (MHLS, DDSO, medical providers).
- After a determination of no objection there is a 48-hour waiting period which allows for any possible change in decision by either party.
- The actual pink MOLST form will be completed by the physician and involved party at the hospital.

Steps to Complete the 6-step Process During Hospitalization Cont...

- Once the MOLST is completed the physicians will provide care according to the MOLST directives currently in place.
- If the person is discharged from the hospital to their residence the MOLST directives remain in effect. A copy will be placed in the person's medical chart, will be made readily available to medical personnel and staff, and Staff will be trained on any LST's being withheld per the MOLST form.



Under the Mental Hygiene Law

- In 7/2022 Legislation was passed for “Supportive Decision-Making”
- **Definitions**
- **Decision-maker:** The person being supported to make their own decisions.
- **Presumption of capacity (82.3):** Every adult shall be presumed to have capacity to enter into a supportive decision-making agreement unless the adult has a court appointed legal guardian. The presumption may be rebutted by clear and convincing evidence.
- **Understanding the “New York’s Family Health Care Decisions Act”**



Under the Mental Hygiene Law (continued)

- A disability does not consulate evidence of incapacity.
- The decision maker can enter into a supportive decision-making agreement if they understand they are making and executing an agreement with their chosen supporters and they are doing so voluntarily.
- The decision-maker can revoke all or part of the agreement at any time.

Under the Mental Hygiene Law (continued)

Supporter: A supporter is voluntary and agrees to assist with the decision-maker in making their own decisions as “prescribed” by the decision-making agreement and who is not ineligible under article 82.08. The supporter is to have undue influence.

Facilitator: Someone authorized by OPWDD that works with and educates the decision-maker and the supporter(s) about supportive decision making and supportive decision-making agreements.





More About Supportive Decision Making

- Supportive decision making is a means by which a decision maker (person supported) utilize support from a trusted circle of support made up of 1 or more persons in their life in order to make their own decisions about their life to include health care.
- It is an agreement the decision-maker (person supported) enters into with one or several different supporters (trusted persons in their life) who will help them make their own decisions.
- It can be an informal decision, or one in accordance to article 82.11 which has been signed by a facilitator.
- Rules and Regulations related to Supportive Decision-Making are not yet complete. The Commissioner of the office for people with I/DD shall announce rules and regulations necessary to implement Article 82 with 1 year. (7/2023)

82.12

Limitations and Liability

- A Health care provider shall be immune from any action alleging that the decision-maker lacked capacity to provide informed consent, unless the entity, custodian or organization had actual knowledge or notice that the decision maker had revoked the supportive decision-making agreement, or that the supporter had committed abuse, physical coercion, undue influence or financial exploitation with respect to the decision to grant consent.
- A physician will be immune from any action related to disclosure of personal information/ medical information about a decision-maker to the supporter unless the physician, supporter or organization had knowledge that the decision maker had revoked such authorization.
- Professionals are not dismissed from liability related to improper, illegal, or negligent professional activity or treatment under this article

Information in its entirety on Article 82:

<https://www.nysenate.gov/legislation/laws/MHY/TEA82>





Frequently Asked Questions (FAQs) by Parents

- **Question:**
- If I am guardian for my loved one, why can't I make advanced directives for them?
- **Answer:**
- A law was put into place in June 2010 to protect people with I/DD that allows for decision making related to LST at the time it is needed but not in advance.
- **Question:**
- When can my loved one appoint an HCP?
- **Answer:** your loved one can appoint an HCP if they have completed a capacity assessment that states the person has the ability to understand what an HCP is, and they have someone they love, and trust involved in their life who agrees to be their HCP.

Frequently Asked Questions (FAQs) by Parents (continued)

- **Question:**
 - Can I be a guardian and HCP for my loved one at the same time?
- **Answer:** It is not recommended that a person supported has both a guardian and HCP as the guardian's wishes will always trump the HCP and this can create unnecessary conflict.
- **Question:**
 - Can I begin the 6-step process now for my loved one so it is complete?
- **Answer:** No, the 6-step process is completed at the time the person may require LST (frequent illness with subsequent hospitalization, diagnosis such as cancer or end stage dementia or end stage kidney failure).





Frequently Asked Questions (FAQs) by Parents (continued)

- **Question:**
- If I choose to withhold life sustaining treatment for my loved one can I then change my mind?
- **Answer:** Yes, the guardian can always change their mind on any paperwork put in place to withhold LST.
- **Question:**
- Can my loved one remain in their home if receiving palliative care or hospice care?
- **Answer:** The person can stay in their home while receiving palliative care, and while receiving Hospice/ comfort care unless we cannot control the persons pain while receiving Hospice at which time they will be transferred to inpatient Hospice until pain is under control. The person would be transferred back to their home once pain can be controlled. Every effort is made not to move someone out of their home.

Frequently Asked Questions (FAQs) by Parents (continued)

- **Question:**
 - Can I bring my loved one to my home when this documentation is in place?
- **Answer:** Your loved one can still come to visit at your home if it is safe for them to do so and you feel comfortable with their care.
- **Question:** Will my loved one still receive needed routine medical care while receiving palliative care?
- **Answer:** Yes, a person receiving palliative care can receive all care previous to receiving palliative care. Palliative care is an added support/service.
- **Question:** Will my loved one still receive needed routine medical care while receiving hospice care?
- **Answer:** Hospice care/ Comfort care focuses on comfort and therefore many of the routine appointments will begin to be cancelled. Appointments to be cancelled should first be discussed with the primary care physician.

