

SDMC Part Two: End of Life Decisions for the Surrogate Decision Making Committee Volunteer

**Presented by the BAEC Committee for the Disabled, Elder Law
Committee and the NYS Justice Center**

January 10, 2019

Welcome and Introduction:

Kelly M. Barrett, Esq., *Chair, Elder Law Committee*
Christopher J. Grover, Esq., *Chair, Committee for the Disabled*

Speakers:

Deirdre Keating, Esq., *Director, Records Management & Access Unit and Counsel to SDMC Program
Justice Center for the Protection of People with Special Needs*

Laura Monthie, BS, RN, LSCW-R, *Director, Surrogate Decision Making Committee Program*

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Justice Center for the Protection of People with Special Needs

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End of Life Decisions

Date: January 10, 2019 1:00 P.M. – 4:00 P.M.

Presenters: Deirdre Keating, Esq. and Laura Monthie, BS, RN, LSCW-R

Agenda

1:00pm – 1:30pm	Legal Background SDMC and Health Care Decisions Act
1:30pm – 2:00pm	Health Care Decisions Act Provisions and Amendments Life Sustaining Treatment
2:00pm – 2:10pm	Break
2:10pm – 3:00pm	Role of the Surrogate Decision Maker Role of the Attending Physician Complying with the Law SDMC EOL Case Forms
3:00pm – 3:10pm	Break
3:10pm – 4:00pm	Evaluating Capacity Burden of Treatment Surrogate Court Procedure Act § 1750-b Process SMDC End of Life Hearing SDMC EOL Hearing Record MOLST Legal Requirements Hospice Admission

Deirdre Keating, Esq.

Deirdre Keating is the Director of the Records Management and Access Unit at the NYS Justice Center for the Protection of People with Special Needs. Among other duties, this Unit is responsible for responding to requests for records and information under various State statutes.

Prior to joining the Justice Center, Deirdre served as a Senior Attorney with the NYS Division of Criminal Justice Services with a primary focus on access to criminal history information issues.

After graduation from Albany Law School and working in private practice, she joined the Counsel's Office of the NYS Department of Correctional Services and worked in the Legislative and Intergovernmental Affairs Unit. She has also served as the Town Prosecuting Attorney for Ravena, NY and the Planning and Zoning Attorney for Rensselaerville, NY.

Laura Monthie, BS, RN, LSCW-R

Laura Monthie is the Director of the Surrogate Decision-Making Committee (SDMC) Program at the NYS Justice Center for the Protection of People with Special Needs. SDMC is a program established by the NYS Legislature in 1988 to provide timely medical decisions for individuals served by the mental hygiene system who lack the capacity to provide their own informed consent and also have no legally authorized and available surrogate to make the decision on their behalf.

Prior to joining the Justice Center, Laura was an investigator for the NYS Commission on Quality Care and Advocacy for Persons with Disabilities. Laura began her career with people with disabilities as a registered nurse and then completed her MSW degree at the University of Albany. She provided advocacy and medical social work services for people with disabilities through early intervention and special education programs, and also residential programs in the Capital District for close to twenty years.



Surrogate Decision Making Committee

CLE, End of Life Care Decisions Volunteer Training
1.10.19

Agenda

- Legal Background
 - SDMC and Health Care Decisions Act
 - Legislative Intent
- Health Care Decisions Act
 - Provisions and Protections
- Complying with the Law
 - SDMC EOL Case Forms
 - The Hearing
 - SDMC EOL Hearing Record

Legal Background: SDMC & The Health Care Decisions Act

SDMC Decision-Making Authority

Surrogate Decision-Making Committee Program

NYS Mental Hygiene Law (MHL) Article 80 Surrogate Decision-Making for Medical Care and Treatment and 14 NYCRR Part 710 Procedures of the SDMC

Health Care Decisions Act (2003)

Article 17-A, SCPA § 1750-b

- Decisions to withhold and/or withdraw life-sustaining treatment
- SDMC added to the list of possible surrogate decision-makers effective 1/1/2009

Legal Background

Basic Right to Consent - Personal autonomy to determine what may be done with his/her body

- Sholendorff vs. Society of NY Hospital, 211 NY 125 (1914)

Right to refuse treatment if competent

- Fosmire v. Nicoleau, 75 NY2d 218 (1990)

Legal Background

- In re Storar, 52 N.Y. 2d 363 (1981), cert. denied, 454 US 858 (1981)
- In re Westchester County Med. Ctr. ex rel. O'Connor, 72 NY2d 517 (1988)
- Cruzan v. Dir., Missouri Dep't of Health, 497 US 261 (1991)
- Blouin v. Spitzer, 213 F. Supp. 2d 184 (N.D.N.Y. 2002) *aff'd*, 356 F. 3d 348 (2d Cir. 2004)

Legal Background

Storar

- A parent/guardian does not have the right to refuse treatment on behalf of a person who has never had the ability to communicate their wishes
- People who never had the ability to communicate their wishes were deemed to *want* treatment

Legal Background

O'Connor

- No firm commitment to decline treatment while competent
- Decision narrowed to patient's expressed intent
- Requires clear and convincing standard

Legal Background

Cruzan

- The state is warranted in establishing rigorous procedures for refusal of medical treatment for persons who are incompetent.

Legal Background

Blouin

- Shelia Pouliot admitted to hospital 12/99
- Family asked to withhold treatment
- Treatment ended, began again, ended
- Appeal to be heard 3/7/00
- Ms. Pouliot died 3/4/00

Legal Background

Blouin

- Alice Blouin, Pouliot's sister, filed federal lawsuit alleging negligence, unlawful practice of medicine, battery, intentional or reckless infliction of emotional distress, and constitutional violations

Legal Background: Prior to the HCDA

- New York State did not allow removal from life support/withdrawal of Life Sustaining Treatment (LST) without a Health Care Proxy
- New York State required LST to continue if an individual had never competently expressed a desire NOT to be treated in such a way

Health Care Decisions Act

SCPA § 1750-b

Legislative History of the Health Care Decisions Act (HCDA)

**Amendment to the Guardianship Statute:
*Surrogate Court Procedure Act (SCPA) § 1750-b***

In 2002, § 1750-b of the SCPA was created to grant authority to Article 17-A guardians to make health care decisions regarding life sustaining treatment for persons with intellectual disabilities.

HCDA: Subsequent Chapters

- Corporate guardians: *Laws of 2003, Ch. 232*
- 17-A guardians for person with DD: *Laws of 2005, Ch. 744*
- Family members: *Laws of 2007, Ch. 105*
- SDMC: *Laws of 2008, Ch. 262*
- Consumer Advisory Board for Willowbrook: *Laws of 2010, Ch. 8*

Legal Background In re M.B., 6 NY3d 437 (2006)

- Whether the HCDA applies only to guardians appointed after March 2003 effective date; or
- whether it also effects the authority of guardians serving before March 2003

Health Care Decisions Act

Applies to All Surrogate Decision-Makers for Persons with ID/DD, including Family Members, Guardians, and the SDMC

Same rigorous standards must be followed by all guardians, including family members and SDMC

Hierarchy of Decision Makers/Possible § 1750-b Surrogates:

1. Court appointed guardian with authority to make health care decisions
2. Actively involved spouse
3. Actively involved parent
4. Actively involved adult child
5. Actively involved adult sibling
6. Actively involved other adult family member
7. The Consumer Advisory Board for Willowbrook Class
8. **A Surrogate Decision-Making Committee**

SCPA § 1750-b(1)(a)

SDMC Jurisdiction for Withdrawal/ Withholding of LST

SDMC authority is restricted to individuals diagnosed with an intellectual or developmental disability

The individual does not need to have received services from OPWDD, only a diagnosis of ID/DD is required to qualify for SDMC.

Health Care Decisions Act

Exceptions

Health Care Proxy (HCP)

If the Patient has a valid HCP, the agent operates outside the scope of the HCDA process

Brain Death

HCDA process is not required in the event of brain death

LST

LST is any treatment which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period

SCPA § 1750-b (4); PHL § 2980 (9-a)

LST Includes

- Cardiopulmonary Resuscitation (CPR)
- Intubation/Ventilation
- Artificial nutrition and hydration (NG, PEG, G-tube)
- Dialysis
- Use of antibiotics, inotropes, pressors, chemotherapy
- Blood transfusions
- Any other treatment the physician deems to be LST

The Role of the Surrogate Decision-Maker in § 1750-b

- Advocate for the full and efficacious provision of health care, including LST
- All treatment decisions made are based on the person's best interests, and when known, the person's wishes including moral and religious beliefs

SCPA § 1750-b (2)(a) & (b)

The Role of the Surrogate Decision-Maker in § 1750-b

Best Interest Decisions are based upon:

- the dignity and uniqueness of the person;
- preservation, improvement or restoration of health
- relief of suffering;
- consideration of the unique nature of artificial nutrition/hydration; and
- the entire medical condition of the person

SCPA § 1750-b (2)(a) & (b)

The Role of the Attending Physician

Capacity Evaluation

SCPA § 1750-b(4)(a)

Medical Condition

SCPA § 1750-b(4)(b)

Notification of the Decision

SCPA § 1750-b(4)(e)

The Role of the Attending Physician

Notifications of the Decision

- The Patient
- Agency CEO or State Operations Office or the Commissioner of OPWDD if person doesn't reside in a voluntary/state operated residence (e.g., Nursing Home)
- MHLS

SCPA § 1750-b(4)(e)

How Does SDMC Incorporate the HCDA?

Complying with the HCDA: The SDMC Process

- SDMC forms require the same HCDA medical and capacity certifications
- Efforts to determine any moral and/or religious beliefs or opinions of the patient
- Notifications are made following the SDMC hearing decision
- Follows § 1750-b decision-making standard
- The SDMC decision is issued in writing and witnessed
- Objection rights and appeal process for SDMC follows the HCDA

Complying with the HCDA: SDMC Forms

- Declaration for End of Life Care (SDMC Form 300)
- Certification on Capacity for End of Life Care (SDMC Form 310)
- Attending Physician and Concurring Physician Certification for End of Life Care (SDMC 320 AB)
- Supplemental Medical Information for End of Life Care (SDMC Form 330)

Two Capacity Certifications: SDMC Form 310

- The attending physician and consulting physician and/or licensed psychologist, must confirm that the Patient lacks capacity
- Both clinicians must document the cause, nature, extent and probably duration of the Patient's incapacity
- One evaluator must have specialized experience with ID/DD

SCPA § 1750-b(4)(a)(b)

Special Criteria for Evaluating Capacity

One of the capacity evaluators must meet one of the following criteria:

- employed by an OPWDD Development Disabilities Services Office
- employed for a minimum of two years in a facility or program operated, licensed, or authorized by OPWDD
- approved by the OPWDD Commissioner

Certification on Capacity (Form 310)

SCPA § 1750-b(4)(a)(b)

Attending and Concurring Physician Certification for End of Life Care: SDMC Form 320 AB

Two physicians certify that the patient has:

- A terminal condition where the patient has an illness or injury from which there is no recovery and which reasonably can be expected to cause death within one year; or
- Permanent unconsciousness; or
- Requires life-sustaining treatment, is irreversible and will continue indefinitely.

SCPA § 1750-b(4)(b)

Two Physicians Certify the Extraordinary Burden of Continued LST: SDMC Form 320 AB

In light of:

- the Patient's medical condition, other than the intellectual or developmental disability;

and

- the expected outcome of the LST, aside from a Patient's intellectual or developmental disability

SCPA § 1750-b(4)(b)

The Life Sustaining Treatment to be Withheld/Withdrawn: SDMC Form 320 AB

- CPR (DNR)
- Mechanical Ventilation (DNI)
- Artificial Nutrition and/or Hydration
- Antibiotics
- Hospitalizations
- Vasopressors

The Extraordinary Burden of Continued Life-Sustaining

Considerations of the impact on the Patient, in light of the medical condition and expected outcome

- Is treatment painful?
- Is it futile?
- Is it without benefit?
- Does it fail to improve quality of life?

Attending and Concurring Physician Certification (Form 320-AB)
SCPA § 1750-b(4)(b)

Burden of Treatment: Considerations

- Pain and suffering outweighs the benefits of LST
- Would the proposed treatment merely prolong the person's suffering?
- Is there any net benefit to the person's functioning or quality of life?
- Is continued treatment futile?
- Any hope of recovery or restoration of function?

14 NYCRR § 710.4 (c)(2)(ii)(A)

Artificial Nutrition and Hydration is Considered Separately

To withdraw or withhold artificially provided nutrition or hydration, two physicians must also agree there is:

- No reasonable hope of maintaining life

OR

- The artificially provided nutrition and/or hydration poses an extraordinary burden

Certification of Medical Need Forms 320 AB

SCPA § 1750-b(4)(b)(iii)

Decision Making Standard: Attestation by the Declarant

No health care decision shall be influenced:

- By a presumption that an individual with an ID or DD is not entitled to the full and equal rights, protection, respect, medical care and dignity afforded to persons without ID or DD; or by
- Financial considerations of the guardian, health care provider, or any other party

Declaration for End of Life Care Form 300

SCPA § 1750-b (2)(a) & (c)

HCDA Special Protections

- Not intended to permit suicide, assisted suicide or euthanasia
- Guardian/decision maker cannot consent to any act or omission the patient could not consent to if capacitated
- All advocacy and health care decision-making is solely and exclusively based on the best interests of the patient

SCPA § 1750-b(1) & (2)(a)

SCPA § 1750-b Process

SDMC Decision is Issued in Writing

Issued on SDMC Form 380-A

- Signed by the panel chairperson and witnessed by the SDMC Coordinator at the hearing
- Consent is valid for DNR/DNI and other orders to withhold or withdraw LST
- All interested parties receive a copy
- There is no expiration date

SCPA § 1750-b(4)(c)

Attending Physician Notifications Include:

- the Patient
- Mental Hygiene Legal Service (MHLS)
- OPWDD State Operations Office Director or the agency CEO of the residential provider; or
- the Commissioner of OPWDD or Designee

SCPA § 1750-b(4)(e)

Notifications

Attending Physician provides notification following the SDMC hearing:

- To **Withhold** treatment - may be implemented after notifications have been made
- To **Withdraw** treatment - attending physician must wait at least 48 hours before **Withdrawing** Treatment

SCPA § 1750-b (4)(e)

Right to Object the Decision

- The Patient
- Parent or Sibling
- Attending Physician
- Any other Health Care Practitioner providing services to the Patient
- Agency executive director/CEO; or DDSO Director
- Mental Hygiene Legal Service (MHLS)
- Commissioner of OPWDD or Designee

SCPA § 1750-b (5)

Objection Process

- Objection may be issued orally or in writing
- Decision to withhold or withdraw LST suspended until objection is resolved
- Objecting party must notify guardian (in this case SDMC) and other parties identified in SCPA § 1750-b(5)(a)
- A special proceeding may commence in a court of competent jurisdiction

SCPA § 1750-b (5)(6)

The SDMC End of Life Hearing

Hearing Participants

- *Patient**
- Declarant, Agency, Hospital Staff
- An Attending Physician in-person or by phone
- Panel Members
- Any Interested Parties or Correspondents
- Mental Hygiene Legal Service (MHLS)
- Local SDMC Coordinator

** Patient will be visited by at least one panel member prior to the hearing*

Panel Procedures

- EOL hearing are almost always Expedited
- Review the case information prior to the hearing
- The hearing is typically held in the hospital but could be held at the Patient's home
- 1-2 panel members will visit the Patient
- Testimony on Capacity-Authorized Surrogate-Best Interests
- SCPA § 1750-b criteria is entered into the hearing record by testimony
- Decision is issued in writing

The Hearing Record Establishes:

- The lack of Capacity to make the decision and the lack of a Surrogate to act on Patient's behalf
- Moral or religious beliefs expressed by the Patient
- The Patient's medical condition
- The LST to be withheld/withdrawn
- The extraordinary burden of the LST/artificial nutrition/hydration

SDMC End of Life Hearing

Opening Statement

Opening statement is read - identification of all present and participating by phone- swearing in witnesses

Capacity and Surrogacy

- The panel member(s) who visited the Patient will objectively state on the record what they observed when they visited the Patient, and objectively make statements about what they felt the Capacity of the Patient was based on the information that they were able to elicit from the Patient.
- Residential staff and Correspondents provide testimony concerning the Patient's baseline functioning, daily routine, previous and present level of functioning; and any moral or religious beliefs expressed by the Patient.
- Testimony establishing the lack of a Surrogate

Clear and Convincing Standard

SDMC End of Life Hearing *cont'd*

<p>Best Interests</p> <p>Preponderance of the Evidence Standard</p>	<p>Medical Condition</p> <p>The panel must obtain testimony to enter the qualifying medical condition on the record. <i>(See page 2 of the Attending and Concurring Physician Certification)</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> Terminal Condition, or <input type="checkbox"/> Permanent Unconsciousness, or <input type="checkbox"/> A Medical Condition that is irreversible, requires LST and will continue indefinitely <p>What is the LST to be Withheld/Withdrawn?</p>
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SDMC End of Life Hearing *cont'd*

<p>The Extraordinary Burden of the LST</p>	<ul style="list-style-type: none"> • What is the LST that is recommended to be withdrawn/withheld? • Why would the LST present an extraordinary burden - in light of the Patient's qualifying medical condition? • What is the medical condition and prognosis? • Likely outcome of LST if continued?
<p>Extraordinary Burden Artificial Nutrition and Hydration</p>	<ul style="list-style-type: none"> • The burden of artificial nutrition and hydration is always a separate discussion. • Testimony to support the reasons why artificial nutrition and hydration presents an extraordinary burden for the patient.

Best Interests Considerations

- Risks, benefits, alternatives, burden of treatment
- Relief of suffering; pain with and without treatment
- Preservation or restoration of function; prognosis
- Improvement in the quality of the patient's life
- Personal beliefs and values of the patient

MHL § 80.3(d); 14 NYCRR § 710.4(c)(2)(ii)(A)

Best Interests Considerations

- The dignity and uniqueness of every person
- Preservation, improvement or restoration of health
- Relief of suffering by means of palliative care and pain management
- The nature of artificially provided nutrition or hydration
- The entire medical condition of the Patient

SCPA § 1750-b (2)(b)

Case Examples

DNR/DNI

Complex Medical Situations

Withdrawal/Withholding of Artificial Nutrition and Hydration

If SDMC does not Consent to Withhold/Withdraw LST

Any party may:

- immediately resubmit an EOL case with new information; or
- submit to the SDMC a declaration for non-emergency medical treatment

14 NYCRR § 710.4 (c)(3) & (4)

MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities

All LST decisions must have a copy of the MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities attached

Hospice Admission Forms

- SDMC Consent is valid for hospice
- Federal and State Laws govern hospice
- SDMC Panel Chairperson may sign hospice admission forms relative to consent for hospice treatment and receipt of notice of patient rights
- Payment authorization for hospice services shall be the responsibility of the director or designee of the patient's residential program per MHL § 33.03

SDMC Contact Information

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