

NICU Palliative Care Needs Assessment

Thank you for participating in our Survey! The following questions will assess: Your experience and comfort with palliative care
The current approach to palliative care in the NICU at Mt Sinai
How palliative care practices can be improved

Your answers are anonymous and will be used for quality improvement and research purposes only. By continuing, you give consent to participate.

You are about to begin a research survey. For information on this research study, please read the attached Research Information Sheet. If you wish to participate in this research study, please continue to the research survey.

[Attachment: "NNA_1_4_HRP-508 Exempt Research Information Sheet (11.11.2022) (1).doc"]

Please create a unique identifier for yourself by:
Writing the name of a favorite pet or TV character followed by a favorite number.
Example: Garfield7

Please indicate the hospital in which you primarily work.

- Mount Sinai Hospital
 Mount Sinai West

What is your role in the NICU

- Nurse
 Attending Neonatologist
 Attending Pediatrician
 Neonatal Fellow
 Resident Physician
 Advanced Practice Provider
 Other

How long have you worked in a NICU?

- < 1 year
 1- 5 years
 5-10 years
 >10 years

How long have you worked in the NICU at Mount Sinai?

- < 1 year
 1- 5 years
 5-10 years
 >10 years

Have you ever cared for an infant receiving end of life care, such as withdrawal of life sustaining measures like a ventilator, or being made DNR/DNI as they were dying?

- No, I have never cared for an infant receiving end of life care
 Yes, one or twice
 Yes, a few (3-5) times
 Yes, many (>5) times

Please answer the following statement:
I have received specific training on how to care for dying infants.

- Yes
 No

I feel comfortable identifying and treating symptoms that come at the end of life, such as pain or air hunger/gasping

- Strongly disagree
 Somewhat disagree
 Unsure
 Somewhat agree
 Strongly agree

What additional training would help prepare you to treat symptoms at end of life?

When babies are dying in my unit, I feel able to adequately control their pain/discomfort

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

What additional supports would improve pain management?

I have the required resources to provide palliative care in the NICU

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

What additional assistance would you like to have?

There is enough assistance from other NICU staff to support babies requiring palliative care and their families

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

What additional resources would you like to have?

The physical environment of my unit is ideal for providing palliative care to dying babies

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

How can the physical setting for palliative care or withdrawal of life support be improved?

There is enough time to provide for the needs of babies requiring palliative care, and their families

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

What do you wish you had more time to do?

When a baby dies in my unit, I have sufficient time to spend with the family

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

What do you wish you had more time to do?

There are policies/guidelines to assist in the delivery of palliative care in my unit

- Strongly disagree
 Somewhat disagree
 Unsure
 Somewhat agree
 Strongly agree

What guidelines would be helpful?

When providing palliative care for infants in the unit, continuity amongst the NICU team working with a patient and family is important

- Strongly disagree
 Somewhat disagree
 Unsure
 Somewhat agree
 Strongly agree

How can continuity be improved?

Parents are informed about palliative care options when appropriate

- Strongly disagree
 Somewhat disagree
 Unsure
 Somewhat agree
 Strongly agree

How could informing parents of palliative care be improved?

I feel included in goal of care conversations with parents

- Strongly disagree
 Somewhat disagree
 Unsure
 Somewhat agree
 Strongly agree

When caring for an infant who is dying, I feel comfortable speaking to parents about the dying process

- Strongly disagree
 Somewhat disagree
 Unsure
 Somewhat agree
 Strongly agree

What areas do you feel uncomfortable speaking about?

I feel comfortable guiding a family through withdrawal of life sustaining therapies/compassionate extubation

- Strongly disagree
 Somewhat disagree
 Unsure
 Somewhat agree
 Strongly agree

What components of withdrawal of life sustaining therapies are you uncomfortable with?

I feel able to express my opinions, values, and beliefs about providing care to dying babies in our unit

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

When is it difficult to express these beliefs?

I feel moral or emotional distress when an infant undergoes withdrawal of life sustaining therapy

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

What supports help with this distress?

I feel comfortable responding to the emotions and grieving process of parents when their infant is dying

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

It is important to not give parents false hope

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

It is important to respect parental wishes for their child

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

Our unit provides adequate bereavement support to families when their child dies

- Strongly disagree
- Somewhat disagree
- Unsure
- Somewhat agree
- Strongly agree

How can bereavement support be improved in our unit?

Our unit has adequate spiritual support for families of a dying infant

- Yes
- No

How can spiritual support be improved?

Additional comments
