Montreal Children's Hospital
McGill University Health Center

Improving Palliative Care in the NICU

NURSING IN-SERVICE WORKSHOP 2018

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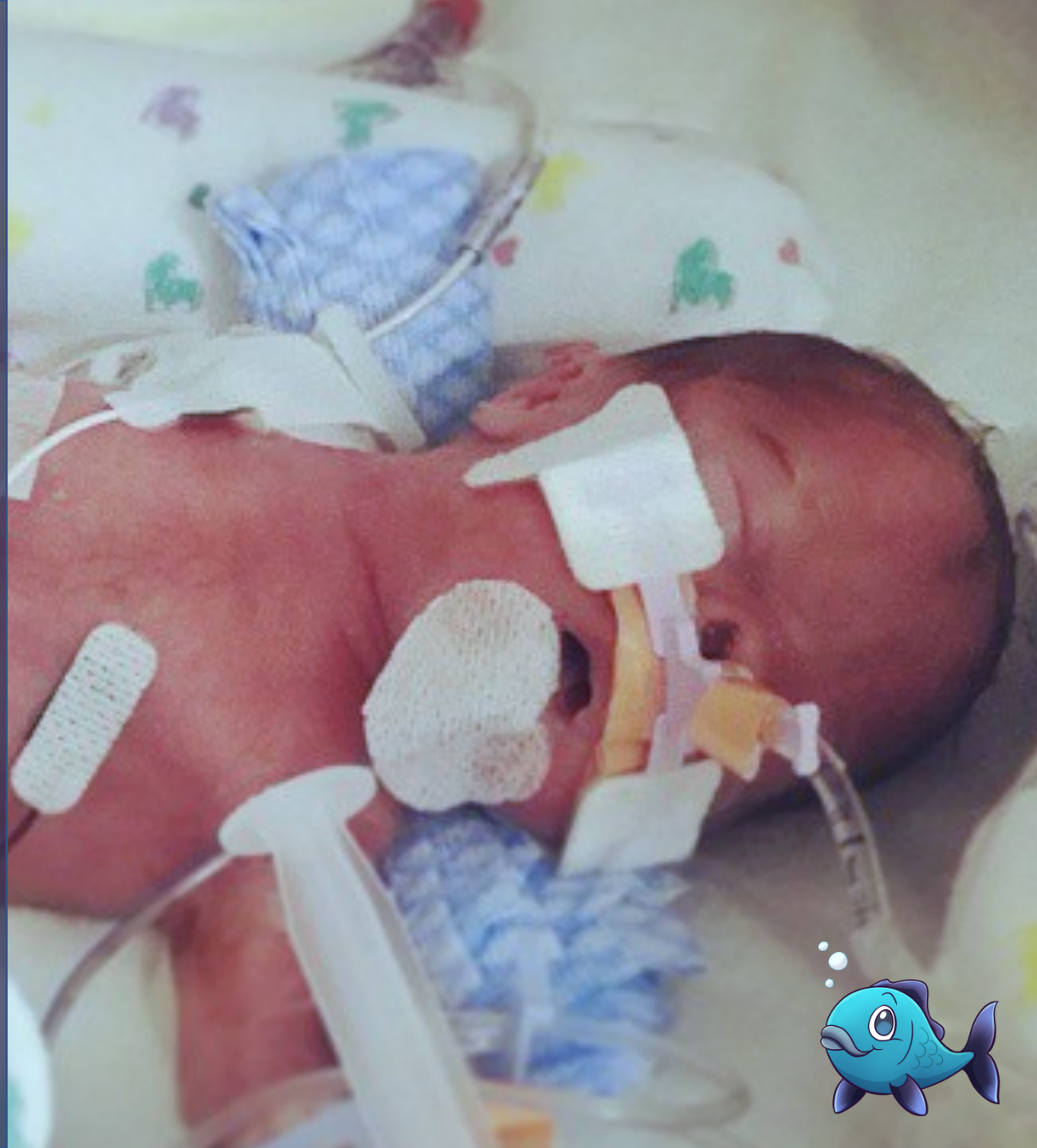


GOALS OF THE MULTI-DISCIPLINARY TEAM

DEVELOPPING AN INTEGRATED APPROACH

IMPROVING THE TRANSITION FROM CURATIVE TO A PALLIATIVE CARE APPROACH

HARMONIZATION OF PRACTICES

DEVELOPMENT OF TOOLS AND CLARIFYING THE PROCESS

BUILDING A SHARED UNDERSTANDING OF THE VARIOUS ROLES OF MEMBERS INVOLVED IN PALLIATIVE CARE

INFORMATION SHARING

BUILDING THE CAPACITY WITHING THE NICU FRONTLINE

PROVIDING EDUCATION

WHY IS PALLIATIVE CARE IMPORTANT IN THE NICU?

SOME COMMON THOUGHTS

Babies aren't supposed to die

Palliative Care means we are giving up

The death of a baby is always:

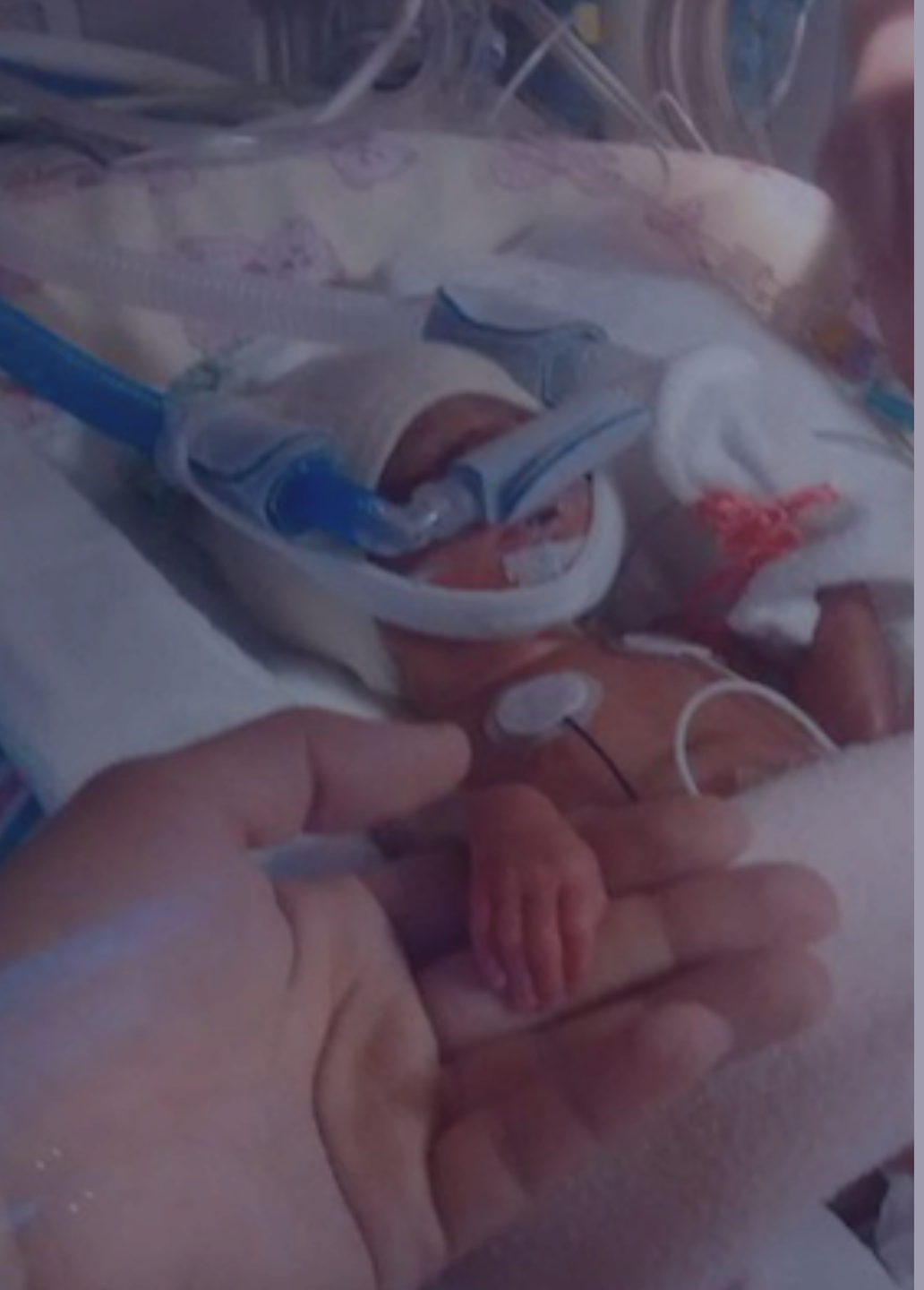
- TRAUMATIC
- UNEXPECTED
- PAINFUL
- DISEMPOWERING

Nothing we can do can help with that…

IS A "GOOD DEATH" POSSIBLE FOR OUR BABIES AND THEIR FAMILIES?

What are the elements of a "good death"?

- MEANINGFUL
- TRUST
- PAINLESS
- ACCEPTED
- UN-RUSHED
- PEACEFUL
- CONTROL



UNDERSTANDING CARE AS A CONTINUUM

VS

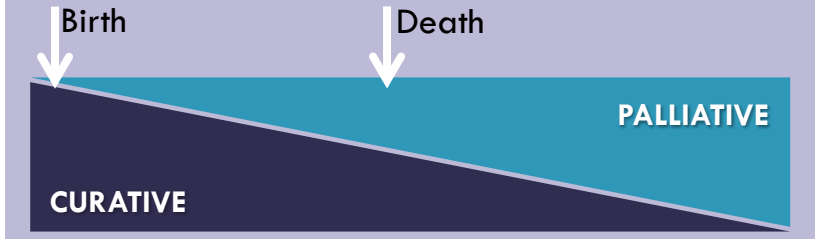
WHAT CAN PALLIATIVE CARE LOOK LIKE IN THE NICU?

Baby A

23wkr
24hr honeymoon – Intubated Fi02 ~45%
Pulmonary Hemorrhage
Grade IV IVH, on Dopa drip, HighFi Fi02 100%
Parents decide to stop invasive care measures
Bb is extubated electively, placed in KC care
Dies with 5hrs

Baby B

Ex 25wkr – now 11months old
Severe BPD, short gut, developmental delays
Unable to wean CPAP below PEEP 11
Baby becomes septic - parents request to not re-intubate at MD's suggestion
Bb dies in mom's arms after 3 days on CPAP, partially sedated, with full TPN and antibiotics

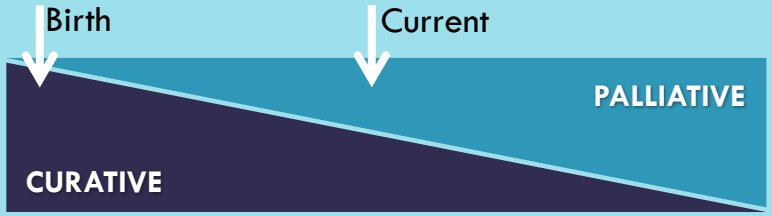


Baby G

Anti-natal diagnosis of Trisomy 18
Neonatal consult, decision made by family and medical team to give palliative care exclusively
Bb admitted to NICU for assessment and palliative care, initially stable in RA.
Baby fed by bottle ad lib for comfort, no NG feeds
Family transferred to LePhare
Baby died spontaneously at 2 weeks of life

Baby J

Term Baby admitted for feeding intolerance and weightloss
3 week NICU stay with uncertain diagnosis
Dx: Microvilus Inclusion Disease – genetic test results
Stabilized on TPN and discharged home
Followed by palliative care team as an outpatient
GI transplant candidate



PALLIATIVE CARE SYMBOL

Meet our new Palliative Care Symbol:

WHY?

IDENTIFY PALLIATIVE CASES

- Improve communication and sensitivity of staff
- Promote respectful and peaceful environment for family
- Improve teamwork

WHEN ?

IMPLEMENTATION:

- As soon as there is a restriction on resus measures
- At the same time as the care plan

WHERE?

- On baby's room door or and privacy screen
- On assignment sheet
- Nursing binder
- Pin for ambassadors
- Bag and Mask Blender

BE READY TO EXPLAIN THE SIGNIFICANCE OF THE SYMBOL TO FAMILIES AND OTHERS PROVIDERS

New Tools for NICU RNs

NICU COMFORT CARE PLAN

Name

Mother:
Father:
Other:

Primary RNs:
Primary MD:
Consultants:

RESUS MEASURES
DATE:

Dx Sx DATE

PARAMETERS

RESPIRATORY
VENTILATORY PARAMETERS
iNO:
Baseline FiO_2:
SpO_2 targets:
Chest Physio: Q
Suctioning: Q
CHEST TUBES
Rt Lt
Sutured @
Inserted
Removed
TRACHEOSTOMY
Trach Size:
Next Trach Δ:
RT NOTES

CARDIOVASCULAR
Vitals Q: BP Q:
Pulses Q:
VASCULAR ACCESS
PICC / CVL: lumen
Fr: Ext. portion:
Inserted:
Removed:
Drsg Δ due:
Insuflon :
UVL UAL
Sutured @
Inserted
Removed
ELIMINATION
Strict In/Out: Yes / No
Foley Inserted:
Ostomy notes:

NEURO / PAIN
Pain/Sedation Scale Q:
Type:
Goals:
Neuro Vitals Q:
GASTRO-INTESTINAL
Wt Q: Lt Q:
HCO: AbdoGirth Q:
Milk Type:
Route:
Frequency:
Duration:
- NG - NJ - OG - OJ -
Inserted:
Secured @:
GT - GJ Size:
Inserted:
Balloon check:
Q: ml:

FLUIDS
TFI: Weight:

Updated by:
Date:

SYMPTOM MANAGEMENT
HYGIENE
Bath Q 1-2 D Last: Next:
Mouth care Q: Chlorhex: Yes / No
PHYSIO
Δ Position Q2-6h (max) Q:
Favorites: Avoid:
ROUTINE
DRSGs
PAIN
MED:
MED:
MED:
Non-pharmacological measures:
SYMPTOMS INTERVENTIONS (pharmacological & non-pharmacological)
RESP / CARDIO / GI

NICU COMFORT CARE PLAN

Privileged Visitors:
Social Support System:
Siblings

Social Worker:
Psychologist:
Translator:
Spiritual Care:

Visit/Call Log : YES / NO Dedicated RN Psycho/Social Notes: YES / NO

Languages:

NEXT MEETING
Goals:
Date: Location:
Participants:

SPIRITUAL BELIEFS
Religions:
Meaningful Rituals and Practices:

PARENT'S REQUEST FOR END OF LIFE

PARENT EMPOWEREMENT
Empower parents to participate in care as much as possible.
List acquired skills and topics for further teaching.
Skills (ex: bath, feed, pump, touch, temp, PO/NG meds, eye care, GT care)
Teaching topics:

EMOTIONAL COPING
MOTHER
Feelings Expressed:
Date:
FATHER
Feelings Expressed:
Date:

PRESENT CONCERNS
Date:

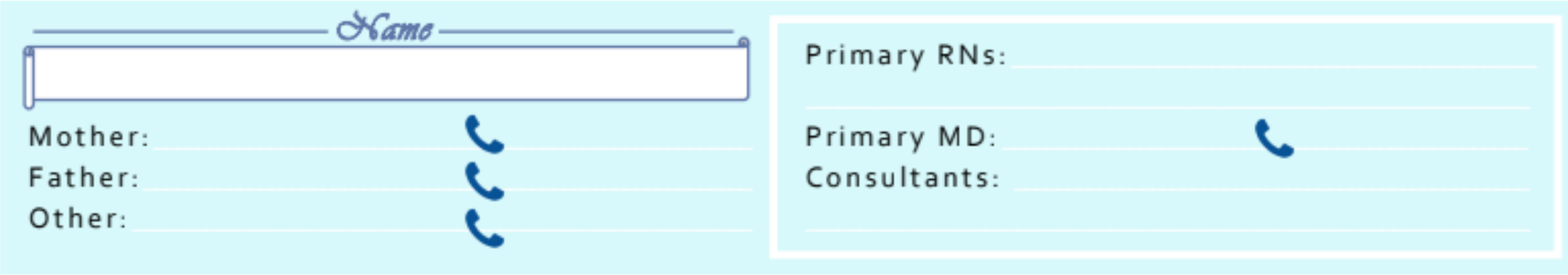
COMMUNICATION TIPS
Ask simple, open ended questions, Be patient, wait for responses, allow for silence, sit together for longer conversations. Involve family in care. Validate their role as parents.
- What is your priority for baby today?
- What is worrying you the most?
- Are there any thoughts that give you comfort?
- Have you been able to talk to anyone (friends/family/etc) about what is going on with baby?

Avoid platitudes: "I understand how you feel" "time heals" "be strong" "baby will be in a better place"

NOTES

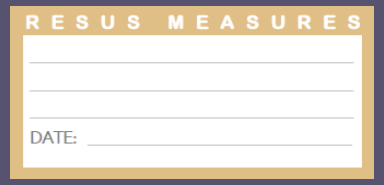
PRIMARIES

Important for continuity of care and building a trusting relationship with the family



Role of the bedside RN:

- Advocate that Baby be assigned a primary staff neonatologist & primary RN
- Explain the role of the primary to the parents
    - Primaries are your advocates and a key resource person, but will not necessarily be assigned to care for your baby all the time



RESUS MEASURES

GOALS OF CARE MEETING

May involve several family meetings before a consensus is reached.

Possible participants: Parents, Primary Neonatologist, Primary/bedside RN, PACT team, Social Worker

Priorities:

- Clarify current medical situation.
- Discuss family values and perspective
- MD: make an expert recommendation to the family that takes their values into consideration
- Come to a consensus about the goals of care and level of intervention.

PRO TIP: RN should sit with/beside family as your role is to advocate for baby and support the family

POSSIBLE OUTCOMES

What is legally required in order to limit resuscitative measures?

DNR or Signed Physician Orders
******NOT progress note******

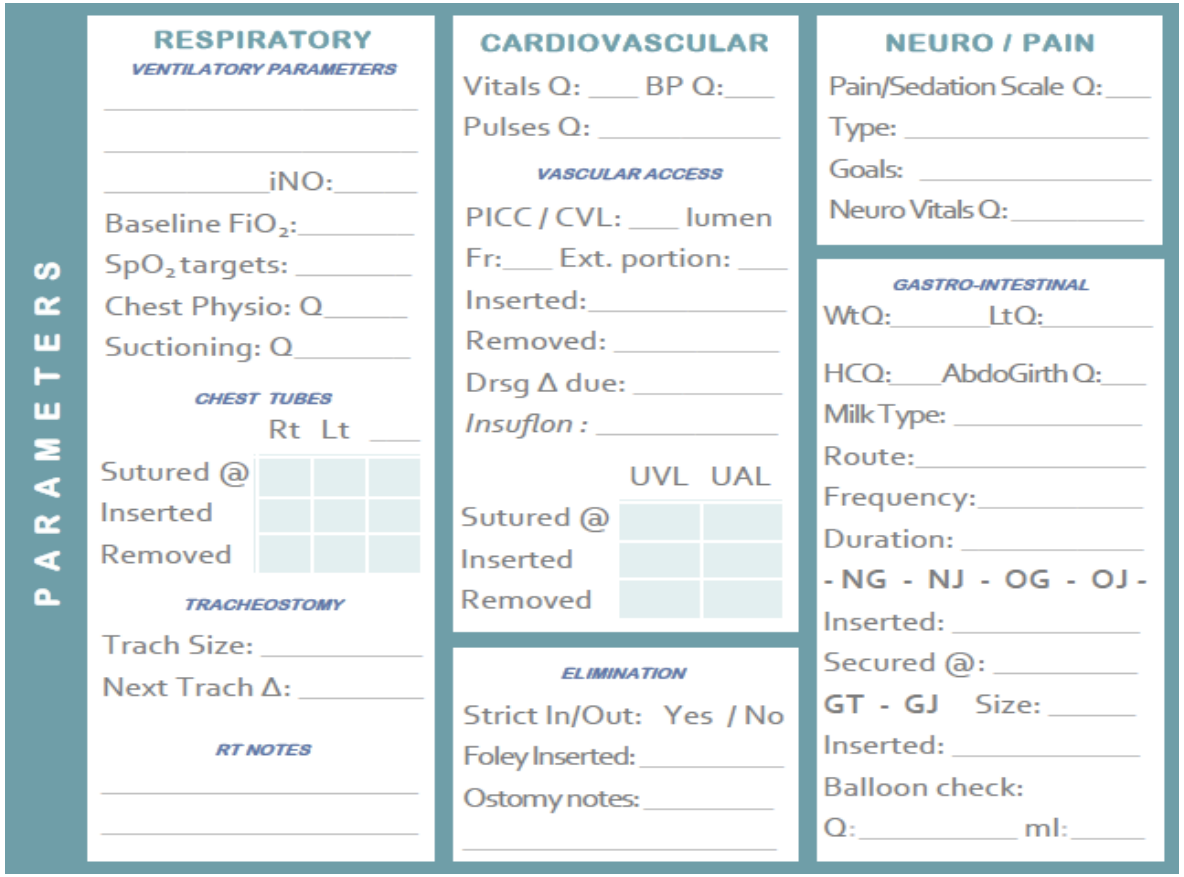
Ex. Bb V: confusion occurred as elements of the DNR were detailed in progress notes and not in the orders.

All PACT team orders need to be cosigned by our medical team

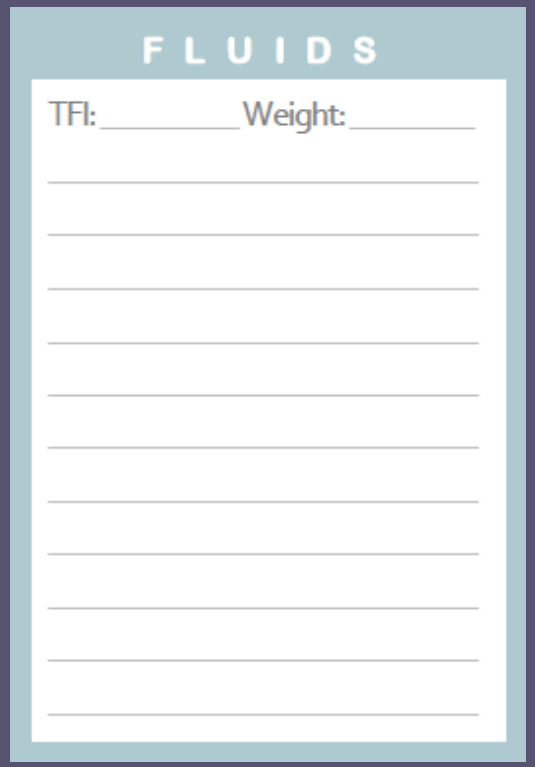
Ex. Bb L: confusion as DNR was signed with PACT team not with NICU team. Staff MD preferred to be present when level of care was decided.

PARAMETERS AND HEALTH HISTORY

Complete: to enable the transition of any baby to any level of palliative care



FLUIDS



Fluid management depends on the goals of care and an individual assessment of the babies needs at a given time.

No one-size-fits-all approach.

Is it ever ethically justifiable to withhold gavage feeds for a baby with no IV fluids?

Ex. Bb R

- Severe asphyxia, hypotonia, severe neurological damage. Parents decide to pursue full palliative care.
    - Do we offer to stop NG feeds?

Is it ever ethically justifiable to withhold PO feeds for a baby with no IV fluids?

Ex. Bb R cont'd

- NG feeds stopped. No parenteral nutrition. Baby will take the bottle a little bit when offered, but is aspirating on feeds leading to increased secretions and increased WOB. Baby does not show signs of hunger.
    - Do we continue to offer bottle? do we insert an NG? do we stop feeds?

STOPPING ARTIFICIAL NUTRITION AND HYDRATION

CULTURALLY feeding is viewed as a symbol of life, non-feeding at end-of-life is often considered unacceptable by family and many health care providers

Feeding = Comfort "Starving" = Suffering

REFRAMING THE ISSUE:

Physiology and metabolism of body at end of life is DIFFERENT than normal physiology and metabolism

- Hunger and thirst decreases significantly after 1-2 days
- Ketone production replaces glucoses needs of infant
- Endogenous endorphins decrease pain perception and can lead to a feeling of euphoria

RISKS ASSOCIATED WITH FEEDING AT END OF LIFE

15% risk of complications with parenteral nutrition

76% risk of complications with enteral nutrition

POSSIBLE COMPLICATIONS

- Infection
- Generalized edema and skin breakdown
- ↑ Respiratory secretions, coughing and gagging
- Electrolyte disturbances
- Nausea, vomiting, constipation
- Pain

ROUTINE NURSING CARE

How to avoid superfluous routine interventions/exams: before any intervention, no matter how routine

Always ask yourself:

What am I (or the medical team) going to do with the information and is it relevant to the goals of care?

Some examples to reflect about:

Auscultation:

None invasive, but do you have a justification?

Ex. If you are concerned about secretions? constipation? It may be useful, it may not be..

Temperature:

Axilla, rectal, touch?

BP/NeuroVitals/Reflexes/weight/abdo girth/length etc.

What will you do with the information?
How invasive is the exam?

How do you respond if the doctor wants to examine the baby?

What will they do with the info? Is it out of routine? Is it a resident/med student who is curious and wants to learn, or a staff preparing for a family meeting? Are the parents present, will it distress them or baby?

What about bloodwork, Xrays, diagnostic tests?

Think critically, remember the goals of care and gently advocate for the baby

SYMPTOM MANAGEMENT

Baby M: Severe asphyxia, parents have decided to withdraw invasive care, Baby is extubated. Baby has been "actively" dying for 3 days, parents have been at bedside and are becoming increasingly anxious as Baby has started gasping and is no longer voiding.

The mother looks to you in panic and asks you if her baby is suffering.

How do you respond? How can we help to prepare parents for end of life symptoms? What *gentle words* can we use to describe the symptoms in a way that parents can understand?

Ex: Dry Diapers (often a distressing end-of life symptom for parents)

RN's knowledge: Baby's kidneys are shutting down because they are not being perfused, he is in organ failure

RN says to parents: Baby's metabolism is ***slowing down*** and his body does not need to produce urine, this is a ***natural end of life process*** and it does not cause Baby any discomfort.

GASPING AND CHAIN STOKES BREATHING

Nurses need to have a clear confident answer to help reduce parent anxiety.
You and your colleagues will likely be asked the same question many times.

IMPORTANT CONCEPTS

- Gasping is an unconscious reflex of the brain
- Baby is not aware of it. Suffering requires consciousness, therefore Bb is not suffering from "air hunger"
- Gasping may not decrease with sedation (ie. Morphine might not help)
- It is a normal part of the dying process, parents should be pre-emptively told to expect it so that it creates less anxiety when it appears.

Often the MOST distressing end-of life symptom for parents

What if the family has questions you do not feel confident answering?
Who can you call to help?

THE PAC TEAM

~

Palliative Care Program

Dr. Liben
Dr. Decell
Evelyn RN

PEDIATRIC ADVANCED CARE TEAM

The program members address clinical issues including pain and symptom management, communication on end-of-life care issues, sibling support, advance care planning, location of care preferences and options, psychological and spiritual assessment, quality of life treatment options, and bereavement support.

When to consult PACT team:

"Would you be surprised if this infant died within the next year?"

NICU Medical Team makes the consult, parents do not have to be involved in the decision to consult PACT team, PACT team can advise medical team without even meeting the family, in some cases; however, they are a great resource in planning the goals of care.

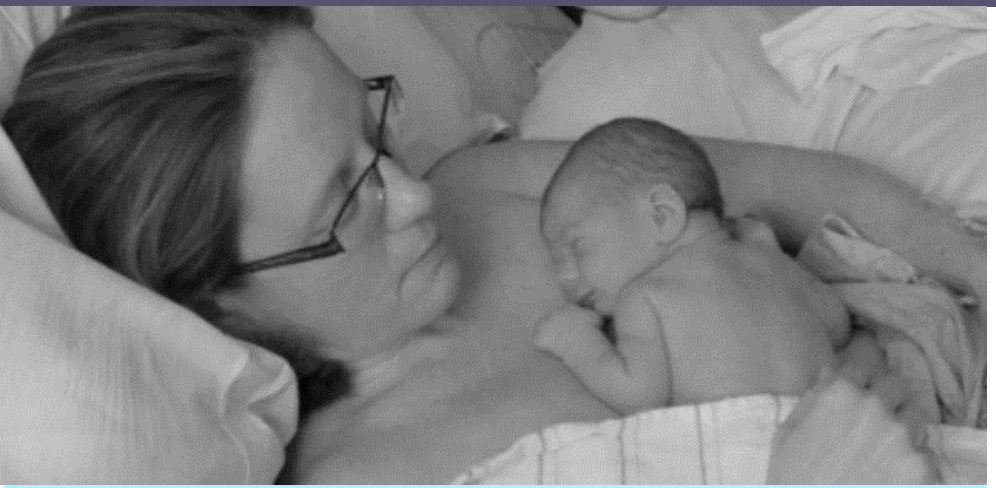
Role of the NICU RN:

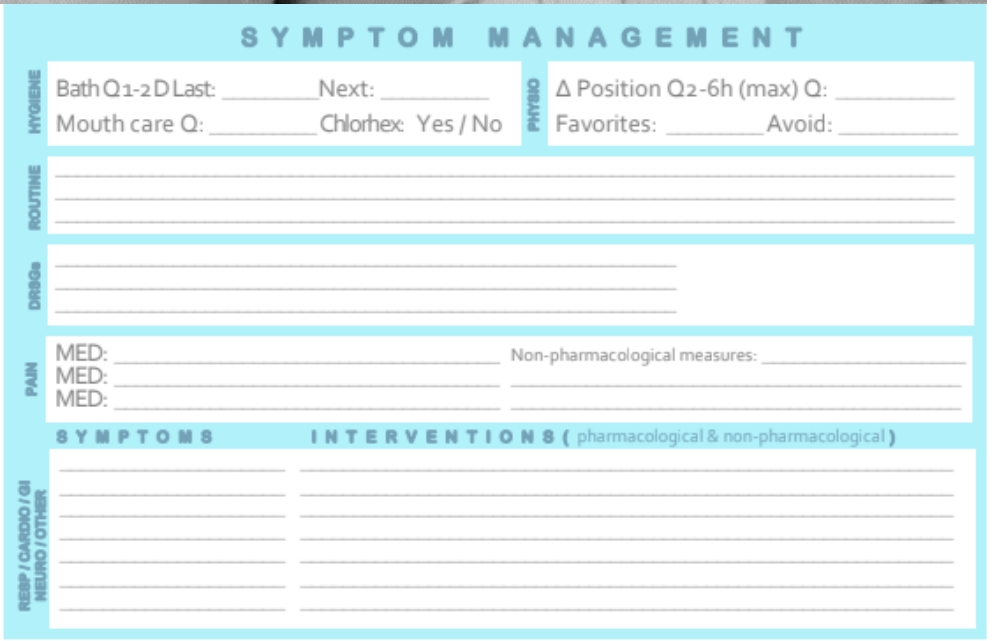
Advocate for your patient's quality of life, be the baby's voice:

"I am concerned about Baby G's comfort and quality of life, given the current situation, and I am questioning the ultimate benefit of the current plan of care"

Remember that palliative care can exist alongside active curative care. Palliative care can start BEFORE we have given up on invasive care. It's a CONTINUUM!

SYMPTOM MANAGEMENT CONT'D




SYMPTOM MANAGEMENT

HYGIENE
Bath Q1-2D Last: _____ Next: _____
Mouth care Q: _____ Chlorhex: Yes / No

PHYSIO
Δ Position Q2-6h (max) Q: _____
Favorites: _____ Avoid: _____

ROUTINE

DRUGS

PAIN
MED: _____ Non-pharmacological measures: _____
MED: _____
MED: _____

SYMPTOMS INTERVENTIONS (pharmacological & non-pharmacological)

RESP / CARDIO / GI
NEURO / OTHER

Case of Baby M (severe asphyxia) continued

Consult the nursing guidelines for non-pharmacological intervention suggestions to help with symptom management, document what works well in the care plan.

Common end-of-life symptoms include:

- Resp Distress
- Seizures
- Constipation
- Dry Mouth
- Pain
- Vomiting
- Congestion

SYMPTOM MANAGEMENT CONT'D

Medical Team or PACT team: Obtain preemptive orders to help you manage expected symptoms, think about your access (IV/SC/PO/NG/INTRA-NASAL)
Ideally, have sedation prescribed with different route options incase you lose your preferred access.

ROUTE	PROS	CONS
UVL	Reliable access, rapid absorption, less invasive	No full bath, less easy to manipulate baby, requires close monitoring, baby cannot be dressed..
PICC	Reliable access, rapid absorption, less invasive, possible to bathe and dress	Requires monitoring, restricts manipulation of baby, risk of infection
PIV	Rapid absorption	Unreliable, requires close monitoring, very invasive installation
SUB-CUT BUTTERFLY	Less invasive than PIV insertion, rapid absorption, reliable	Site rotation q3-5 days + PRN, risk of induration, bruising and cellulitis
OG/NG/PR	Minimally invasive, reliable	Aspiration, absorption? Slow acting
PO	Least invasive	Aspiration, absorption? Slow acting, unreliable dosing
NASAL/SL	Reliable, minimally invasive, rapid absorption	Not applicable for all meds


QUESTIONS?

PSYCOSOCIAL CONSIDERATIONS

PSYCHOSOCIAL SUPPORT

The family's social network (friends, family etc) is as valuable as our healthcare team when it comes to providing psychosocial support to families.

DEDICATED PSYCHO-SOCIAL NOTES

IMPORTANT *for tracking psycho-social issues longitudinally, progress notes on flow-sheets are regularly thinned and the info gets buried and difficult to track.*

Especially useful in Palliative care to improve therapeutic relationships and continuity of care.

MCH PSYCHO-SOCIAL RESOURCES

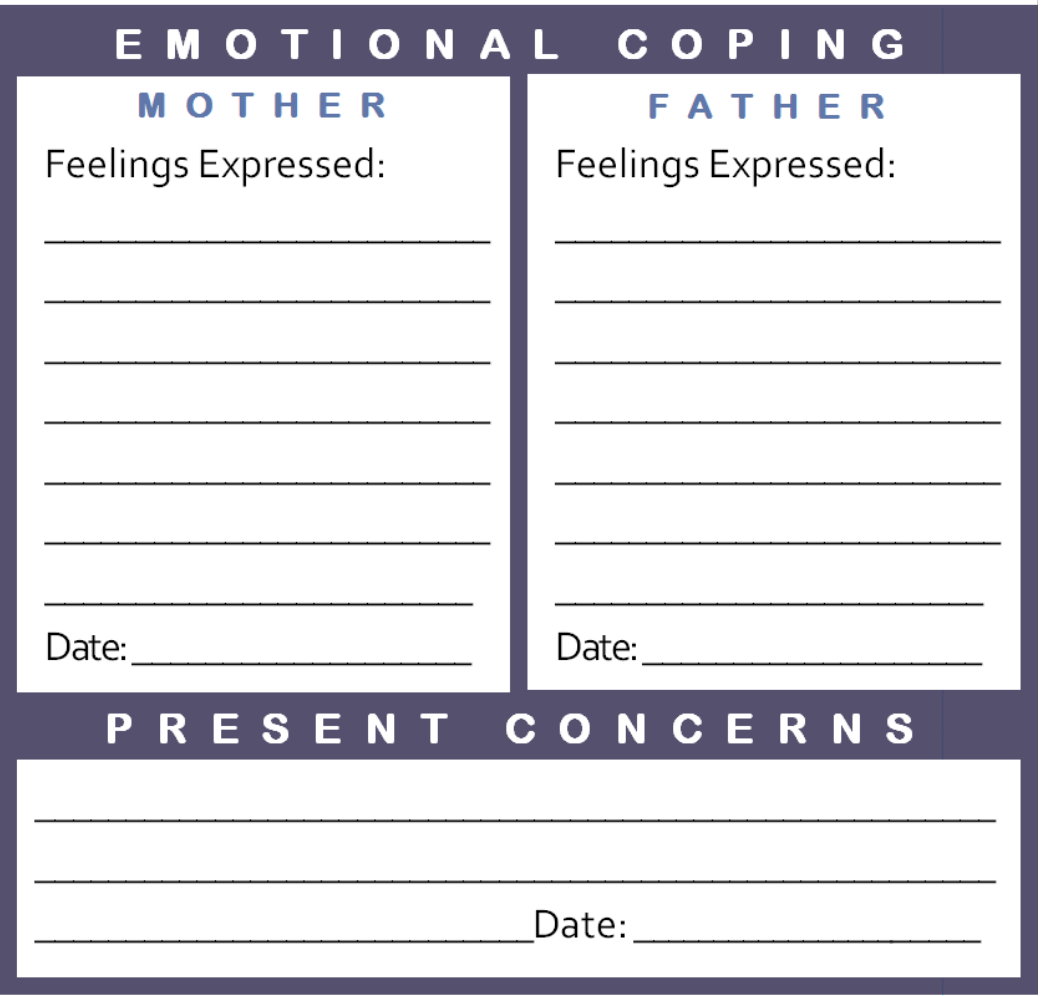
Spiritual Care: emotional, spiritual and emotional support.
(RN can request consult for family)
Availability: on-call 24h/7days week

Social Workers: Supportive counseling, legal/financial
(RN can request consult for family)
Availability: Monday-Friday 9-16h

PACT team: Supportive counseling, complex care coordination, conflict resolution, support NICU staff
(RN CANNOT request consult, but may contact team if concerned once PACT is already involved)
Availability: Monday-Friday 9-16h
& on-call for phone consults

MUHC Psychologist: Supportive counseling in complex circumstances (RN can request consult for family)
Availability: Monday-Friday 9-16h

EMOTIONAL COPING



IMPORTANT TO ASSESS PARENTS INDIVIDUALLY AS COPING OFTEN VARIES BETWEEN MOTHER AND FATHER

CAREPLAN DOES NOT REPLACE Psycho Social notes
Always chart relevant conversations in psycho-social notes

Purpose of the care plan notes are to provide the next nurse with a general pulse (impression) of how the parents are coping

The date can updated without changing the info IF it is still relevant

Are you able to sleep?

Have you been able to talk to anyone about what is going on with baby?

What is worrying you the most?

What is your priority for baby today?

Are there any thoughts that give you comfort?

SOCIO-CULTURAL CONSIDERATIONS

Languages: _____

SPIRITUAL BELIEFS

Religions: _____

Meaningful Rituals and Practices: _____

_____

_____

PARENT'S REQUEST FOR END OF LIFE

_____

_____

_____

_____

_____

LANGUAGES

Communication is central to providing good palliative care.
There is an important distinction between casual fluency in a language and complete comprehension.
Ex. routine care ***vs*** goals of care meeting.
Does your family need a translator?

SPIRITUAL BELIEFS

Religious Identification ≠ Spiritual Beliefs
Spiritual Care are a fantastic resource for helping to clarify with family the beliefs and practices that are important to them.

Be aware of the major role that cultural and spiritual factors can have on decision making

Be mindful of your own beliefs and implicit judgements

REQUESTS FOR END OF LIFE

Ex. Baths and body handling post-mortem, baptism, family presence, hand molding, prayers, wishes etc.

PARENT EMPOWERMENT

Even the parents of dying babies want to feel like PARENTS – help them

PARENT EMPOWEREMENT

Empower parents to participate in care as much as possible.
List acquired skills and topics for further teaching.

Skills (ex: bath, feed, pump, touch, temp, PO/NG meds, eye care, GT care)

_____

_____

_____

_____

Teaching topics: _____

_____

_____

_____

Lactation consultation re–milk suppression/donation ☐

JUST DO IT.

MEMORY MAKING

WHY IS IT IMPORTANT?

Common parental fear is that the child will be forgotten and his life will not have had meaning

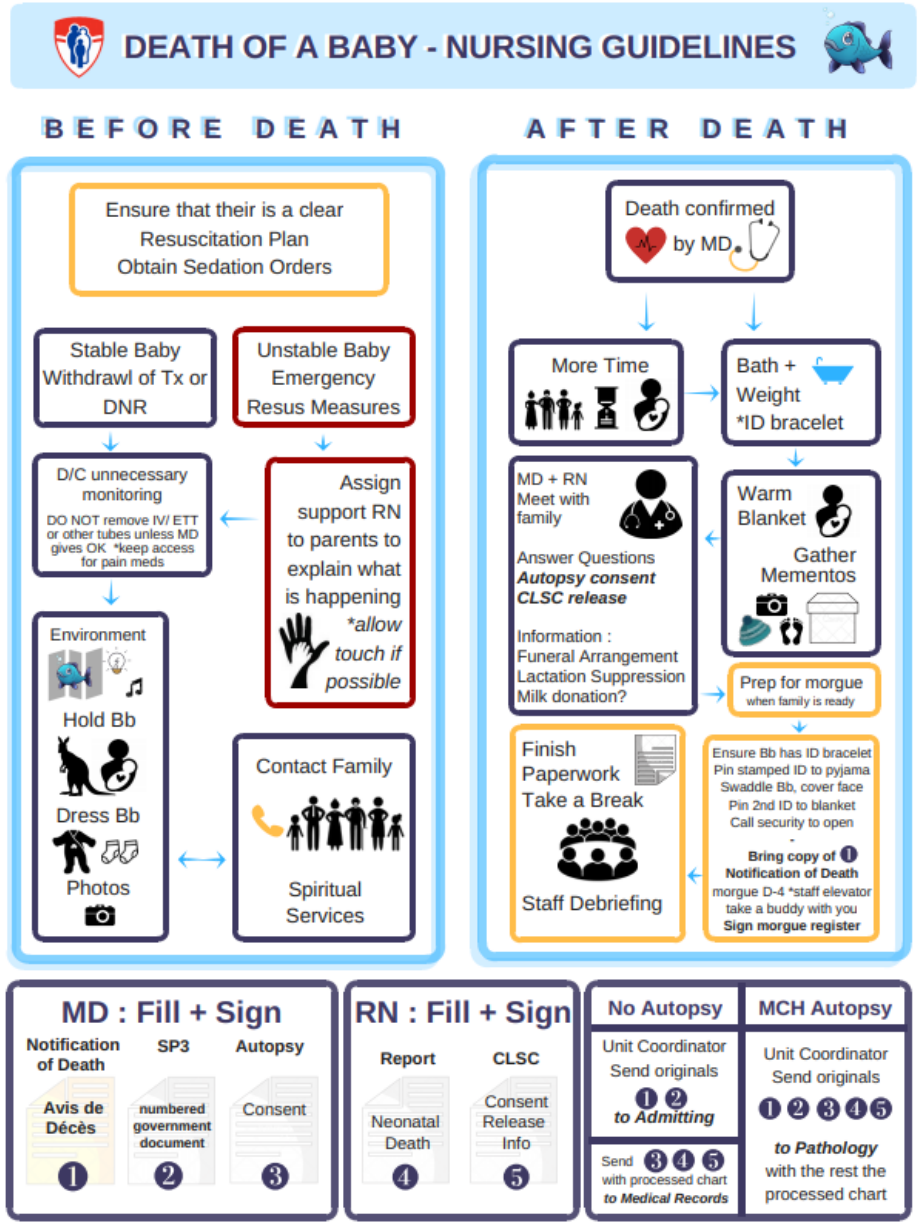
Helps family to emotionally and psychologically prepare family for baby's death.

Reduces stress and anxiety, improves social interactions and gives the family something positive to do with their child and helps them create meaningful memories of their child's life.

****MEMORY MAKING IS NOT JUST FOR TIME OF DEATH****

See NICU Palliative Care Guidelines for more ideas

WHEN A BABY DIES



FOLLOW UP FOR PARENTS

What can parents expect?

Who does the follow-up?

SELF-CARE

Have compassion for yourself

There is no such thing as perfect care or a perfect death - strive for "good"

BE PRESENT for your coworkers
OFFER, ASK and ACCEPT help

ADVOCATE for a debriefing

Know your resources people:
Palliative Care Ambassadors, NICU management
Medical Team, PAC team
Spiritual Care, Ethics

PALLIATIVE CARE AMBASSORS

RESPONSIBILITIES

- Be familiar with the NICU Palliative Care Program and Guidelines
- Have knowledge of resources for memory making activities
- Have knowledge and experience with process and paperwork surrounding a neonatal death
- Have strong communication skills and self-awareness
- Know appropriate uses of our symbol :

ROLE

- Introduce yourself to nurses who are caring for an active or potential palliative case
- Offer to assist them in filling out the Comfort Care Plan
- Advocate for an appropriate primary nurse for palliative babies
- Provide support to new nurses taking care of families receiving a palliative care
- Help to educate your coworkers and the families in the NICU about the nature of neonatal palliative care
  - Help dispel myths and change the cultural attitude with regards to this essential type of care