

A DYING BABY

AND HIS FAMILY

Materials

- Memory box
- Papers (available at the blue nursing station on the bottom racks):
 - Déclaration de décès (SP-3 form)
 - Avis de décès/Notification of Death
 - Autopsy consent or denial form
 - Guidelines for Assisting Parents Around Newborn Death
 - Neonatal Death Report
 - Stamp progress notes with baby's addressograph card (required for future nursing follow-up notes)
 - Authorization to release information contained in the medical record (for the CLSC)
 - +/- lactation suppression information
 - Funeral arrangement information
- 2 index cards (or white piece of paper, stamped with baby's card)
- Identification bracelet
- Materials for a bath

Before a baby dies

- Offer support from spiritual care and/or social work, as appropriate.
- If a decision to stop treatment (or to extubate the infant) is made and time permits, **remove** such invasive items as the **Foley catheter, cardiac monitor, electrodes, saturation probe, Replogle or nasogastric tubes**. It allows the parents to have a last image of their infant without too much medical equipment. Whenever possible, keep an intravenous access in case the infant requires sedation or pain relief. The option to give fentanyl and/or midazolam intranasally also exists. Morphine can be given po. Several medications, including morphine and midazolam, can also be given subcutaneously.
- Whenever possible, **dress the infant in pajamas, a wool hat, mittens, and booties** before death. Clothing, in different colors and sizes, is available in the developmental care room in the first hallway. These items are then given to the parents after the death to keep as mementos.
- Offer the **parents time alone with their baby** and extend this offer to grandparents, friends, or other relatives that the parents may wish to have present.
- **Take photographs** of the infant while alive if possible. When possible, use the parents' camera or phone. A camera is also available in educators' office. If you use the unit's camera, the first picture should be of the addressograph for identification purposes. (Please refer to section on guidelines for taking photographs for ideas and tips to make these photos special). If the baby has been alive for less than a month, the family could also be offered the services of the Portraits d'Étincelles Foundation (<https://portraitsdetincelles.com/>). Please contact the palliative care nurse or spiritual care for information.

After a baby dies

- Go get **memory box** if not already done. They are in the developmental care room in the first hallway.
- Remove catheters and electrodes (including peripheral arterial line). Leave CVLs, UVLs, UALs, and chest tubes in place.
- Give the infant a **quick bath**. Offer to involve the **parents** in this care if they wish.
- **Weigh** the baby. This additional statistic can then be added to the **baby's identification card and vaccination booklet/"carnet de santé"** that are given to the parents. They appreciate these fine details.

- **Dress the infant** in cute pajamas. The parents may prefer to dress the infant in a sleeper they have brought, or alternatively, you will find cute clothing - pajamas, hats, and blankets - in the drawers of the developmental care room of the first hallway. **Wrap** the infant snugly in a **preheated blanket**.
- **Ask the parents if they want to hold their baby** and leave them as much time with their infant as they wish. For parents who at first refuse to hold their baby, sometimes simply explaining to them that in your experience other parents have later found this helpful will be enough to change their minds. Likewise, if you hold the dead infant and appear comfortable in this role, the parents will be encouraged that this is a "normal" thing to do.
- After asking for the **parents' permission, collect as many mementos as possible** for them. (Please refer to the section entitled "Souvenir and Memento Collection" later in this protocol).
- While the parents are holding their baby, take the time to **change the infant's bed** and make it look clean and fresh. Do not remove the baby's bed from the room until the parents have left.
- Make sure a **nurse is present** with the parents when the **doctor asks for permission for autopsy**. It is important to offer support and make sure the parents know that their decision does not have to be taken immediately.
- Take the time to speak to the family about **funeral arrangements** and encourage them to personalize this experience as much as possible. Offer the document ***Making arrangements for your child's funeral*** to the parents. Encourage them to contact the funeral home of their choice when they feel ready. There is no emergency for them to contact a funeral home. Alternately, Wray-Walton-Wray (514-483-2320) and Magnus Poirier have been known to provide good service for a fair price- cremation is free for children under 1 year old.
- Tell parents that it is normal to have a variety of reactions within the next few weeks. An information package on grief will be sent to their home by mail in the next few days. **Please make sure that we have the right address on the hospital card and in Oasis**. Books and pamphlets for siblings are available in the developmental care room in the first hallway. Other books on grief are available if the family wishes additional literature at a later date.
- Provide information on **lactation suppression** if appropriate. Basic advice includes telling the mother to avoid nipple stimulation, apply ice or cool compresses, take Tylenol PRN, and that she can expect engorgement for 3 - 4 days.

Souvenirs and memento collection

- Offer photographs:
 - *Take a variety of different poses.*
 - *Take a close-up photo of the face.*
 - *Take a photo of the infant on a pretty blanket. (Lavender, purple, and royal blue colours are recommended; try to avoid pale colours). Positioning a roll under the baby's neck may help to keep the baby in proper alignment.*
 - *Take a photo of the baby in each of the parents' arms.*
 - *Take a family photo (both parents with the baby and/or with siblings).*
 - *Take a photo of the parents' choice.*
 - *Take a photo of the baby naked (even if abnormalities exist).*
 - *Take a photo which includes a nurse, a person's hand, or someone holding the baby in their arms.*
 - *If the baby is one of twins or triplets, take a photo of both/all babies together.*
 - *Include the baby's toys (large or small) in the photo; they help to personalize the photo and show the baby's relative size.*
- **Offer the mittens, booties, hat and/or blanket and clothing worn by the baby.** If you know that the baby is about to die, a good trick is to put these clothing items on the baby before death. These may be the only clothes that the baby will have ever worn.
- Ask the parents if they would like a **lock of their baby's hair**. (**Be careful, not all religions allow this). If the hair is cut around the region of the neck, the missing hair often does not show.
- Offer to do a **footprint and handprint** using the heel print paper kept in the developmental care room (to the right of the "Books for Babies").
- Complete the infant's "**Carnet de santé**". Place it in the memory box for the parents to keep.
- Put in the memory box:
 - *Infant's identification bracelet*
 - *Identification card*
 - *All personal belongings (toys, clothes, pacifier, measuring tape, etc.)*
 - *Foot and hand prints*

– Lock of hair

- If the parents refuse the above items, please identify them and leave them for the palliative care nurse. Tell the parents that these items will be kept and that they should feel free to contact us if ever they change their minds.

Paperwork

- Your **charting** should include a brief **description of the events** surrounding the baby's death. Document in the nurse's notes the post-mortem care and your **interventions with the family**, along with the parents' reaction. The baby's post-mortem **weight** should also be included on the graphics sheet. You should also fill out the **Guidelines for Assisting Parents around Newborn Death** document.
- Have the doctor complete the following:
 - Déclaration de décès (formule SP3)
 - Avis de décès (yellow form)
 - Autopsy consent or denial form
- Have the unit coordinator or team leader advise Admitting (22317) of the death.
- Complete the following papers for the bereavement follow-up nurse:
 - Neonatal Death Report
 - Authorization to release information contained in the medical record (for the CLSC)
- The secretary will complete the chart. The chart should be sent to the appropriate department as per table below:

If there is no autopsy	If there is an autopsy at the City Morgue Tel 514-873-1845	If the autopsy is done at the MCH
<p><i>Send to Admitting C RC 5200:</i></p> <ul style="list-style-type: none"> • Completed and signed (Yellow) notification of death form order #3101014417 • Quebec government form SP-3 	<p><i>Send to Admitting C RC 5200:</i></p> <ul style="list-style-type: none"> • The completed and signed (yellow) Notification of death form order #3101014417 • The SP-3 goes with the body to the City Morgue 	<p><i>Send to pathology D04.2230 (Autopsy Room):</i></p> <ul style="list-style-type: none"> • The (yellow) Notification of death form order #3101014417 • Quebec government SP-3 form • Signed authorization for autopsy and for the removal of tissues and organs form. • #3101014671 (English) • #3101014672 (French)
<p><i>Send to medical records:</i></p> <ul style="list-style-type: none"> • The patient's chart 	<p><i>Send to medical records:</i></p> <ul style="list-style-type: none"> • The patient's chart 	<p><i>When autopsy is complete send to Admitting C RC 5200:</i></p> <ul style="list-style-type: none"> • The completed and signed (yellow) notification of death form order #3101014417 • Quebec government SP-3 form
<p><i>Send to pathology E04.4246:</i></p> <ul style="list-style-type: none"> • A copy of the yellow notification of death indicating no autopsy 		<p>When autopsy is complete, send to medical records:</p> <ul style="list-style-type: none"> • The patient's chart

Before accompanying the baby to the morgue

1. Complete **two index cards** (one index card should be taped to the infant's pajamas and the other card on the exterior of the baby's blanket) with the following information:
 - baby's addressograph
 - birth and death weights
 - birth date and death date
2. Verify that the baby is wearing an **identification bracelet**.
3. **Call security** (78282), they will meet the nurse at the morgue to open the door.
4. **Accompany the baby** to the morgue, **completely covered** in a blanket, using the **staff elevators** only. Don't be shy about asking someone to come with you. The morgue can be accessed through the 4th floor.

At the morgue

- The morgue is in Block D, 4th floor (Room D04.1220).
- Leave **one index card on baby**.
- Put the **other one in pink box** (Pediatric side).
- **Sign** the register along with the security person.
- **Place** the baby in one of the first two doors on the left that say "pediatrics".

Take it easy and be good to yourself. Dealing with the death of a baby is never easy.