

ELNEC COVID-19 Communication Resource Guide

Helping Families Saying Goodbye Virtually to Loved Ones in the Nursing Home and Hospital

Care at the end of life has always been a fundamental aspect of the nursing role. In the final hours of life, nurses care for the patient by promoting their comfort and supporting families. To achieve this, the nurse's presence is essential as they have the most contact at the bedside of patients.

Nurses use excellent physical assessment skills to treat pain, dyspnea, cough, delirium. (*See the Symptom Management section for infographics on how to manage symptoms in people with COVID-19*). They tend to emotional, social, and spiritual needs in the context of the patient and family's culture, communicating with and collaborating with interdisciplinary team members., the nurse also supports families in helping them say goodbye. In times of conventional care, the nurse role models caring behaviors and prompts the family in what to say by the bedside. They include the family in providing comfort measure such as oral care, eye care, lip care, and skin care. They encourage repositioning, touch or massage. Finally, they encourage the family to create a peaceful environment through prayer, music, songs, poetry.

Care during the COVID-19 era is often delivered under contingency or crisis standards of care. Therefore, the nurse's bedside support is not possible due to visitor restrictions in nursing homes and hospitals. This means there will be no family vigils at the bedside in which nurses provide coaching of a peaceful, dignified death to families. Even if one family member is allowed, it may be rare the make it to the bedside in time since patients decline rapidly and there may not be time for travel to the hospital. Closure at the end of life must be conducted virtually.

Therefore, it will be essential that the nurse provide intensive caring with their presence and help the family say goodbye via technology. The nurse's role is role is to be an empathetic support to the family, an avatar of their presence within the dying process. Nurses offer touch and soothing statements as requested by the family. It can feel overwhelming, however it offers the family a priceless gift of saying goodbye.

PREPARING YOURSELF TO HELP A FAMILY SAY GOODBYE

- 1) Expect to have your own emotions arise about an impending death of a patient.
- 2) Draw upon your inner strength and nursing skills that you have in care at the end of life.
- 3) Don't let feelings of guilt about the patient's death without family take over. Rather Accept your feelings and focus on offering a priceless gift to the family
- 4) Determine the resources you have – Do the best you can do with available resources.
- 5) Try to stay present in the moment and not anticipate every emotion of the family and the patient, if they are alert.

PREPLANNING WITH THE FAMILY

- 1) Arrange a preplanning call with the surrogate decision-maker or family organizer.

- 2) Acknowledge that you can't imagine how they are feeling.
- 3) Tell them your role and what you will do and what technology you have (i.e. a smart phone, tablet, or patient room phone).
- 4) Provide simple answers to questions in accordance with patient/family understanding/readiness for responses.
- 5) Educate the family in how they can say goodbye via technology.
- 6) Provide them with information about potential platforms – Zoom, Microsoft Team, Face Time, House Party to have many members attend as desired. Of note, Zoom, Microsoft Team are both HIPAA compliant.
- 7) Encourage them to reach out to family members ahead of time to determine the platform and download the necessary applications, and do a practice session.
- 8) Assist in planning what they will say. Encourage use of reminiscence, song, music, prayer, poetry, stories, readings and photographs that are associated with spirituality or religion as well as important memories or experiences. Also encourage the family to give permission to the family member to let go and reassurance they will be ok afterward.
- 9) Some examples include:

<p>Thank you for the ... I will never forget when we ... You are the reason I learned to appreciate ... I've been thinking of you. I remember when ... Without you, I would have never discovered ... I am so grateful that you taught me the importance of ...</p>

- 10) Tell them to trust their instincts, not "the rules." Since they know their loved one best, they will know what their loved one would find comforting and soothing.
- 11) Help them to anticipate the emotions and feelings of saying goodbye
- 12) Prepare the family for what they will see and hear in terms of interacting with their loved one (e.g. any IV lines, breathing tubes, pumps, monitors, alarms, etc.) Ask the patient and the surrogate decision-maker for permission to describe the loved one's condition at the beginning of the call.
- 13) Remind them to plan and prepare any children. It is important to prepare children for what they are likely to see and experience. Some children will have a need for a lot of information, including what could happen as death draws near, while others will need information only about what is happening now. Encourage them to follow the child's cues for how much information the child wants. Include input from a child life specialist if available.
- 14) If the death will be a discontinuation of the ventilator – make sure they understand that you will premedicate the patient for comfort and to avoid dyspnea.
- 15) Ask what other questions or concerns they have.
- 16) Ask what else you can do to support them?
- 17) Encourage them to call back with any questions or concerns.

SAYING GOODBYE

NURSE PREPARATION IMMEDIATELY BEFORE THE CALL

- 1) Review the information for the family-selected platform chosen for the call with the device or format for communication of which the call will occur – smart phone, tablet, or room telephone.
- 2) Assure access to the device and that it is charged.
- 3) Review the necessary precautions for the technology. For Smart devices, they will need to be in a plastic bag. You will need to make sure the settings are correct so they can see the patient’s face.
- 4) Dial in all the numbers or the platform, so that when it is time, you are just hitting the dial button.
- 5) For ventilator discontinuation - Administer any medications for comfort.
 - a. If a discontinuation of a ventilator, determine with the team when the family will be called.
 - b. Make sure to another clinician is in the room to attend to the discontinuation while you attend to the family.
- 6) Remember your role will be to provide presence: be available, listen, reflect, and connect.
- 7) Connect with the platform.

FAMILY CALL

- 1) Connect with the family via the planned platform.
- 2) Let family know you are with their loved one. If using a video platform, show caring acts like hand holding or compassionate touch
- 3) If there is a larger family group attending the goodbye session, facilitate a meaningful and loving experience, prepare the family with a description of what their loved one will look like. This may include the presence of an endotracheal tubes, intravenous lines, soft wrist guards, pumps, or ventilator machines.
- 4) Instruct them that the patient can hear them even if unconscious. Encourage them to keep talking even if they are not sure they are being heard.
- 5) If their loved one is awake and alert - encourage the family to follow dying person’s lead. If the person talks about impending death either directly or indirectly through metaphor, go along with that.
- 6) Remind them that they should do what feels right and important. Speaking from the heart is best.
- 7) Encourage them to offer meaningful closure statements:
 - a. Talk about how their loved one mattered
 - b. That the love one ere important
- 8) Letting go - It’s OK, even comforting, to let on that they know the end is nearing and they are saying goodbye. You may offer the family to use the following statements with their loved one:

I forgive you Please forgive me Thank you I love you Goodbye (Byock 2014)

- 9) Provide assurance to the family that the patient will not die alone.
- 10) If the family wants to stay until the patient dies, maintain your presence and stay next to the patient.
 - a. Honor the families requests for you to touch their loved one’s cheek, or face, or reassure the person that “X loves you” or “X wants you to be with God.”
 - b. Let the family know of any response such as a hand squeeze, a blink of the eyes, a movement of the head so they can be hopeful that their loved one heard them

AFTER THE CALL

- 1) Continue to stay with the patient. Often once patients have been given permission to let go, they will.
- 2) If there seems to be more time and the patient will have a longer dying process, continue to offer presence to the patient, as allowed by staffing and shift changes.
- 3) Perform your own closure rituals which may include:
 - a. Offering gratitude for being part of their care
 - b. Offering the patient Godspeed on their journey
 - c. Offering the patient a prayer
 - d. Offering a loving-kindness metta such as the following:

May you be filled with loving kindness.

May you be well.

May you be peaceful and at ease.

AFTER THE DEATH

- 1) Provide post-mortem care with colleagues per organization policy and procedures.
- 2) Work with the team to inform the family.
- 3) If possible call them to let them know that the death was respectful and the patient was not alone.
- 4) Debrief with interdisciplinary rounds about how the death went.

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