

### Preliminary guide for professionals: Delivering bad news to families in the Corona crisis

These days, as we deal with the Corona pandemic, its unique conditions of hospitalization, isolation, and distance, it is especially important to pay attention to the process of saying goodbye to a terminal patient. The inability to provide the patient a choice in end-of-life rituals, along with the lack of close physical touch, may increase the fear of death and the difficulty in coping with the loss and grief.

Therefore, the presence of the medical staff, and social workers along the staff, patients and family members in the end-of-life process is more important than ever, and complex. With that, the unavoidable dilemmas and emotional burden that come along. These dilemmas may be deeper in light of the tension around medical decisions under extended stress on the available systems and resources.

### Contact with families/close ones (friends, paid home nurses)

It is recommended that communication with the families will be done through a staff member who is able to provide the necessary attention to the matter, instead of one who is under stress and perhaps even isolated themselves. The contact person should be updated on the medical condition of the terminal patient, and should take part in delivering the bad news. We recommend it to be: doctors, social workers, or nursing staff experienced in empathetic, psychosocial communication.

#### Values and principles for communicating with patients and families

Respect, cultural sensitivity, empathy, companionship, presence, listening, and compassion.

## Adjusting the SPIKES model - Delivering bad news to families (and patients as needed) in the Corona crisis

### **SETTING UP**

- 1. Determine where and how the conversation will take place. The ideal scenario is face-toface when the family arrives to the isolated area. If this is not possible, the conversation should take place using a video-based platform (WhatsApp, Zoom, Skype).
- 2. Ensure a quiet and private environment, even on a digital platform. Pay attention to the visual background (what is seen behind the deliverer) and background noises.
- 3. Self-presentation of the deliverer with name and role, since it is possible the receiver of the news is not familiar with the staff or deliverer.
- 4. Check and determine who should be present in the conversation.
- 5. Check who the patient would want present in the conversation, and ensure ample time to invite and connect them.
- 6. Update the family on how much time is remaining.
- 7. Try and keep **eye contact**, which is very important since communication is at a distance.
- 8. **Example for verbal communication:** "It is important for me to allot you time and attention."

### PERCEPTION

- 1. Ensure an understanding (by asking directly, if needed) exactly what information they already have, and what already has been said; what the family knows about the condition of their loved one (in case the conversation is an update of a worsening condition: what they know about the next steps, the emotions that will come along with the next step, and the medical terminologies for those).
- 2. Identify the emotional state of the family/patient: denial, anger, fear, anxiety, helplessness, uncertainty. Pay attention to the feelings of guilt that may arise due to the manner of saying goodbye the difficulty of physically sitting by their loved ones through their last moments.
- 3. **Example for verbal communication:** "What do you already know? How do you understand the situation? What do you know about their condition? What have you been told?"
- 4. Acknowledge and state: "What you are dealing with is very difficult and terrifying."

### INVITATION

1. Clarify just how willing the family is to have the conversation, and prepare them (can be done with a single sentence) to the news they are about to hear about their loved ones.

### 2. Example for verbal communication:

- a. "Sadly I have bad news for you."
- b. "To our dismay, the situation has worsened."
- c. "Would you like for me to deliver you all the medical information regarding the condition of your loved one?"
- d. "When time is running out, what is the most important thing for you?"
- e. "What is important for you that we know about your loved one (the patient)?"

3. Avoid saying: "We failed, there is nothing left to do, what we tried didn't help, etc."

# This is where the delivery of bad news takes place: following the preparatory sentence, the bad news must be delivered. Following which, any additional information must be provided.

### **KNOWLEDGE & INFORMATION**

Providing the family a sense of companionship/

- 1. Use clear and non-vague terms (such as: "they're gone..." or "they're no longer with us..."), and avoid using terms like: "there is nothing left to do."
- 2. Provide information about what to expect regarding the feelings of the patient, or the upcoming medical procedures.
- 3. Provide information about the procedure in the hospital/country, to the best of your knowledge. This includes what will be done or not done (relocating the patient to the ER, connecting the patient to a ventilator, etc.). Emphasize these steps as procedures for all hospitalized patients.
- 4. Example for verbal communication:
  - a. When the news is about an expected/unexpected worsening of the condition: "I wish this was different, but unfortunately the condition has worsened / going in a bad direction / your loved one is in a life-threatening condition / we expect to have to anesthetize and attach them to a ventilator / they are currently under anesthesia and attached to a ventilator."
  - b. When the news is about death: "I'm sorry, (name of patient) has passed away."

### **EMPATHY**

- 1. Attend to the emotional responses of the patient and their family.
- 2. Identify and attend to the emotional state after delivering the bad news: deep sorrow, denial, anger, anxiety, helplessness, uncertainty, guilt.
- 3. Hold space for the emotional turbulence: crying, cries of pain, drawing in.
- 4. Let the family feel your attachment and care for them.
- 5. **Example for verbal communication:** 
  - a. "This is a very difficult loss."
  - b. "I am saddened by the loss you are experiencing."
  - c. "You had no control over this, you did everything you could."
  - d. "I am sorry you have to say goodbye this way, I would like to offer you..."
  - e. (If it is within your capacity:) "This is a difficult moment, if you would like, I could stay by your side throughout the various next steps."
- 6. (Ideally, the news is delivered to the family at a time when the patient can still communicate, in which case, offer to connect them with a closed-circuit screen, video chat, or phone call).

- 7. In case the patient is anesthetized and attached to a ventilator, you may still offer the family:
  - a. "The sense of hearing is the last to function, therefore, you can still communicate your thoughts and feelings. We can do this via:"
    - i. Write what you would like to tell your loved one and staff members (recommended only for staff with prior familiarity with the patient), which we will then read to them.
    - ii. Record a message for your loved one which we can play for them.
    - iii. When possible, include the family via video during the moment in which you deliver their words to the patient.
    - iv. Offer the family: "Is there anything else you still want to tell your loved one, or something you wish to take the time to say again?"

### SUMMARY

- 1. Ensure that the family/patient received the information and **understood** it.
- 2. Receive information from the family about how they would like to say goodbye, and assist them in coordinating this.
- 3. (If it is within your capacity, and in accordance with your role,) continue to escort the family and ensure there are plans for where and how the burial will take place.
- 4. Identify the family's support system: Who else will be by their side? By phone/video (at this time, we can consider neighbors as well as volunteers).
- 5. Consider providing the family video footage or photos of their loved ones throughout the disease and end-of-life (so they may have memories for the future).
- 6. Offer and ensure the family a continued support and contact in the community, and inform them who they will be able to keep in contact with as needed.
- 7. Examples of verbal communication:
  - a. "Did you receive all the information you need, and do you understand it?"
  - b. "Could you think of the best possible way, considering the circumstances, to say goodbye?"

### For the staff member:

In the case where the family shares with you their last words for the patient (whether you are asked to read it to them, are present in their video call, etc.), it it of utmost importance for you to validate their words:

- Mention that the patient can hear their words, even if they cannot respond.
- Ask the family to speak slowly and take their time.
- At the end of the conversation with the patient, remain with the family a few more moments to check how they are feeling and validate their words:
  - "What you said was beautiful and meaningful."
  - "From your words it is clear to see how dear they are to you."
  - "If I were to hear such things I would feel extremely loved and appreciated."

### The pause

"The pause" is an invitation for a moment of silence, held in the hospital after the death of a patient. It enables closure for the medical staff along with the patient's family. It is a simple ceremony which holds the spotlight on this moment, and sanctifies it. By participating in the moment of silence, the staff members, who may belong to varying religious and cultural backgrounds, come together in ceremony and honor the deceased. The ceremony serves as a tool for self-preservation and buffer against burn-out.

Each one of the staff members may request a "moment of silence" in the appropriate time. Should it not be possible right away, a later and more convenient time should be picked, where all staff members may attend. There is an added benefit to including the family of the deceased if possible, as it emphasizes the importance for the moment for all.

The verbal invitation to the moment may be phrased: "If we could please pause and honor the person laying before us. They lived a full life, and now, they are gone. This person loved and was loved. They were somebody's friend, and family. In this moment of silence we express our appreciation and respect for this person, and all efforts we made to save them. [moment of silence]. Thank you everybody."

### Self-preservation for professionals

These are tough times, and the emotional and technical burdens are especially high. It is crucial that you protect and care for yourselves. You may be experiencing multiple difficulties at once:

- Concern for your own family and their health under these circumstances. Including the family (appropriate to age) in these concerns, and discussing possible solutions to minimize the danger may help decrease the weight of the responsibility you are carrying. It is easier to hold concern and responsibility when they are shared.
- A sense of helplessness in the face of difficult situations (especially whether we can overcome the lack of resources and difficult decisions it calls for). Remember what you **can** do, and the ways in which your work contributes and benefits even when the situation is extremely difficult: listening, educating about the foreseeable future, assisting in preparation, physical or emotional presence. All of these are critical and meaningful.
- Concern about the anger and frustration of patients and families. Remember that the source of anger for the family is being unable to help, and their perceived responsibility to care and love for their loved one being taken away from them.
- Difficulty navigating between the demands of your home and family, and work. As possible, try to schedule set times to be with your family and disconnect from work. Even 15 totally dedicated minutes (phone aside) can be meaningful.
- In case you work from home, the blurring of boundaries may become even more confusing. Pre-determine your work hours and inform your house members of them, along with when you will become available (if unknown, tell them you will let them know later). Try to initiate intentional transitions between work and home life, for example: a

verbal statement that you are now available; a shower; a change of clothes; a short walk outside; a cup of coffee.

- Concern about burn-out and automatic functioning.
  - Notice emotional and physical signs, on yourself and your colleagues.
  - Moments of compassion and assistance try to choose one small moment a day where you connect to another person, assist a patient or one family. These small moments are a huge accomplishment in these times, and will contribute to your sense of importance and meaning.
  - Moments of enjoyment and relaxation even just a couple minutes where you do something that brings you joy or calms you: music, conversation, mindfulness, meditation, a cup of coffee.
  - Moments of release and breathing sit comfortably, inhale and exhale calmly and comfortably, more slowly and deeply than usual, and release tension from your muscles. Take a minute like this every few hours in the day. Breaths are the most effective tool for protecting your physical and mental systems from overstress.
  - Share your experiences with close ones.
  - Share your experiences with colleagues one of the most important factors of resilience is the ability to share your feelings and experiences with fellow staff. Try to make time for this, since you all share similar experiences.
  - If you are unable to hold a conversation, write in a journal. You may also photograph and jot down a few words by the photos, in order to mark meaningful moments every day.
- Concern about physical exhaustion. Make sure to rest and meet your basic needs: sufficient water and nutritious meals. These days it is especially important to protect physical resilience. Remember that doing so will protect your ability to continue helping others. Additionally, try to engage in short physical exercise appropriate for closed space, and to spend time outside in the sun at least once a day.
- Finally remind yourselves that this is temporary, and until it passes, you have the privilege of giving to others, while learning important self-growth lessons yourselves. The events of these times will induce deep changes in all of us, individuals and organizations. It is up to us to create the meaning of these changes, now.

We recommend utilizing the VITALtalk document from which this guide has been created: <a href="https://www.vitaltalk.org/guides/covid-19-communication-skills/">https://www.vitaltalk.org/guides/covid-19-communication-skills/</a>

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