

Responding to hard questions and emotional distress about COVID-19 from dialysis patients or their families

Maintaining Emotional Balance in an Unbalancing Time

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Responding to hard questions and emotional distress about COVID-19 from dialysis patients or their families

Approaches to communication and responding to emotion



Three topics:

Acknowledge and respond to anxiety and fear

Recognize the dialysis center as important source of stability and routine

Honor the memory of patients who have died

3 Strategies for responding to anxiety and fear



Connect and invite response



Acknowledge emotion



Remind about resilience

Connect



DO: Connect and invite

Connect by inviting patients to share their concerns:

- “I’d like to hear what’s on your mind about this.”
- Sometimes people don’t like to admit they are upset, and it shuts them down. Sometimes it helps just to share with another person.
- Check in: “I’ve heard some others express that this coronavirus really scares them. I want to check in and see how you are doing in response.”

Acknowledge emotion



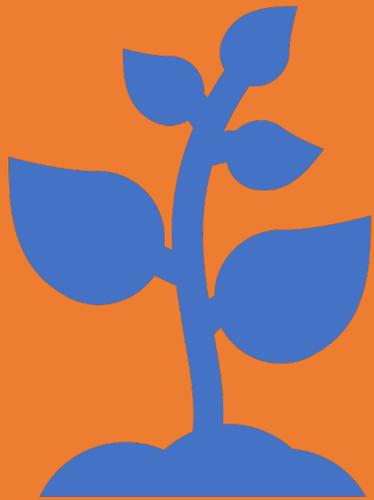
**DO: Acknowledge and empathize
with emotion**

Use empathic statements that
accept difficult emotion

- “Sounds like you have been fearful about what might happen to you and your family. There is a lot that is unknown right now and everything is changing very fast.”



Foster resilience



DO: Foster resilience

Remind patients of their resilience and successful coping strategies:

- “What has helped you get through difficult times before?”





Resilience – Additional resource

Excellent summary of evidence-based tips for resilience:

A psychologist's science-based tips for emotional resilience during the coronavirus crisis

- https://www.washingtonpost.com/lifestyle/wellness/anxiety-coronavirus-mental-wellness-tips/2020/03/16/f187faf2-67b8-11ea-9923-57073adce27c_story.html

Dialysis center as source of stability



Most people are comforted by the routine and the familiar.



The larger context is extreme disruptions at home - children or grandchildren staying home from school, adults tele-commuting to jobs, or wage earners whose jobs have dried up.



The regularity of coming to dialysis, seeing familiar staff and patients, may be very important source of stability.

Maintain
routine –
prepare for
disruption



Maintain routine where possible

If consistent with infection control procedures:

- Do your best to maintain usual schedule.
- Let patients use their own chairs if possible.

Prepare for changes

- Prepare patients for the fact that some things aren't going to be normal.

“Everyone does better when they know what to expect. There is a lot changing all around us, so some routines might be disrupted. We are going to do all that we can to provide a sense of routine. We will also try to openly communicate with you if things need to change.”

Several decorative yellow brush strokes of varying lengths and orientations are scattered in the bottom right corner of the slide.

Honor the
memory of
any patients
who die



It is comforting to know you
will be remembered



Rituals help us remember and
cope with loss

Acknowledge
and honor
the memory
of those who
have died

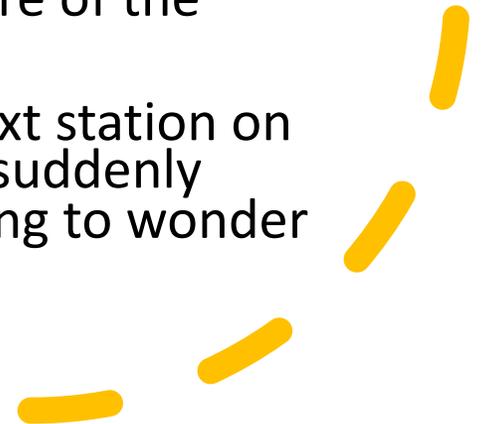


Not acknowledging a loss can make it harder

- Our first instinct might be to downplay attention to any patients who might die during this pandemic. We don't want to frighten patients or dwell on difficult topics.
- But a “conspiracy of silence” leaves people alone and lonely with their questions, concerns, and grief.

People are ALREADY thinking about the person who has died

- The reality is that people are already aware of the heightened risk of death.
- If a person who has been sitting in the next station on the same shift for the past three years is suddenly absent, the patients around them are going to wonder what happened, even if they don't ask.



People fear
being
forgotten

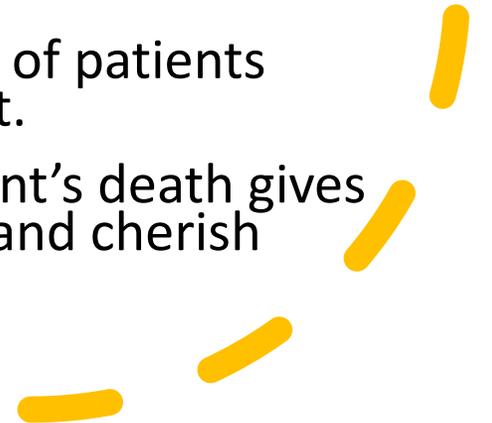


People fear being forgotten

- One of the major fears that many people have about dying is that they will be forgotten.
- If even the memory of their life is erased, it compounds the distress, that it will be as though even the memory of their life is erased.

Respectful remembrances can comfort the living

- Memorials and respectful remembrances of patients who have died can be a source of comfort.
- Open acknowledgement of another patient's death gives the message that we will remember you and cherish your memory even after your death.



Words for telling patients that another patient has died

“We are like family here. I have some difficult news to share. Given how much I care about each of you, I wanted to tell you myself. Unfortunately, Ms. S. has died.”

{Pause; let person respond.}

Name emotion they show.

“This is heartbreaking for me. It is okay to be really upset or even angry right now. We are here to support you and to listen. We may not know the answers, but we are in this together.”

Words for responding if patient's family member has died

- “I heard this morning about {USE FIRST NAME}.”
- If you can remember anything about the caregiver state it. For instance:
 - “Linda always had the most cheerful smile.”
 - “I always could tell that James loved you.”
 - “We are going to miss the way Thomas always joked with us.”
- Name the emotion.
 - “This is so heartbreaking.” “This is a lot of sorrow and loss for you to bear.”
- Let them know that you can tolerate the emotion.
 - “Something like this can make a person so overwhelmed, angry and devastated. You are safe to talk about any of that with me.”



The importance of presence

- When dealing with death, your presence is far more important than the precise words you choose.
- Most people struggle to sit with a person in grief, which can be very lonely for those that are left alone.
- The most important thing you can do is to sit with someone in their time of greatest pain and hold that pain with them.
- You don't need to say much. "I am here for you" is enough.

Do's and Don'ts when discussing death of a patient or family member

Don't:

- Do not attempt to fix.
- Do not discourage emotion.
- Do not try to persuade a different point of view.
- Do not get distracted during conversation (don't look at phone, computer, etc.).

Do:

- REFLECT back and NAME the emotion.
- Let them know that you can tolerate their difficult emotions by holding back your own responses.
- Be present.
- A moment of shared quiet can build connection.
- When it is time to say something: "Take your time. I am here."

Some practices that other health care providers have used



Place a rose on the chair or bed of a patient who has died and leave it unoccupied for a period. (May not be practical in facilities at capacity. Place rose on a shelf or table.)



Make an *in memoriam* bulletin board with notices of the person's obituary, notes from staff about what they enjoyed about the person, possibly from family members. (Need to be careful about privacy and have permission to post.)



Display a ritual memory object, such as a wreath that staff ties a ribbon on for each person who has died, or a small fountain where a beautiful stone is placed for each person who has died. A small ritual to add the person to the object can help provide a bit of closure for staff as well as patients.



Send a bereavement card to family from the dialysis center staff.

More resources for communicating about difficult subjects

Vital Talk has posted **COVID-ready communication skills: A playbook of VitalTalk Tips**

- This is excellent. Gives you the words to say in very difficult situations.
- <https://docs.google.com/document/d/1uSh0FeYdkGgHsZqem552iC0KmXlgaGKohl7SoeY2UXQ/edit>

Social Work Hospice and Palliative Care Network (SWHPN) has posted **Working with families facing undesired outcomes during the COVID_19 crisis**

- <https://swhpn.memberclicks.net/assets/01%20Working%20With%20Families%20Undesired%20Outcomes%20COVID19.pdf>

Resources about palliative care during epidemic/crisis:

- A Field Manual for Palliative Care in Humanitarian Crises: <https://global.oup.com/academic/product/a-field-manual-for-palliative-care-in-humanitarian-crises-9780190066529?cc=us&lang=en&>
 - Chapter 2: Palliative Care Needs of People Affected by Natural Hazards, Political or Ethnic Conflict, Epidemics of Life-Threatening Infections, and Other Humanitarian Crises: <https://oxfordmedicine.com/view/10.1093/med/9780190066529.001.0001/med-9780190066529-chapter-2>

Let us know what other communication
and emotion dilemmas you are facing

Call 202.994.7969, Email kidneycoalition@gwu.edu, Tweet [@kidneycoalition](https://twitter.com/kidneycoalition)



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