

COVID19 and the Relief of Suffering

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Case study

- Deborah W. is an 89 year old resident of a NYC long term care facility.
- She has a close and loving family who visit daily, and a group from her church who come often to pray and sing with her. She looks forward to these visits with joy.
- She develops increased sleepiness and stops eating. Because other people in her facility have tested (+) for COVID-19, she is tested and placed in isolation. No visitors. No staff without mask, eye protection, and gowns and gloves. Her test comes back (+).
- She becomes agitated with rapid heart rate and breathing.
- Her family declines hospitalization because of what they've been seeing on TV.

Case study, continued

- Deborah W. is frightened of the staff because of what they are wearing. When they try to hold the phone to her ear so she can speak to her family she can't hear and gets more agitated.
- Oxygen is not helping to calm her or slow her breathing.
- What should the staff do?

Sources of Suffering in COVID-19

- Loneliness, social isolation
- Shortness of breath
- Delirium- altered level of consciousness likely due to severe infection and change in her environment.

- Staff set up a conference call on zoom with Deborah W's family in her room, so they can see her and try to talk to her. They see how hard she is breathing and that she can't talk on the phone. The conversation goes like this:

NURSE	FAMILY
Hello is this Mr. W? I'm the nurse taking care of your mother. This is not an emergency.	Thank goodness!
I understand your mother has tested positive for COVID	Yes. We're very worried. I feel so bad that she got it in the nursing home. I thought that place would be safe.
Anyone would be worried. And there is no way you could have known this would happen.	I guess...
ASK: Is it ok if we talk about what COVID means for your mother?	Please.
ASK: May I first ask if you are the person who helps make medical decisions for her?	Yes. I'm her proxy or whatever you call it. I have the papers.

TELL: I need to give you some background. Most people who get COVID have a mild or moderate illness and don't need the hospital. The people who most often get a severe pneumonia with COVID are older and have existing medical problems, like your mother.

You know, I've heard that on the news but have been afraid to think about it.

Well that's a very normal reaction. COVID has put all of us in a tough situation.

Yes. And I know that you are so busy.

We are doing our best under the circumstances. So I hope your mother has a mild case and can stay where she is. We will give her all the treatments we can at the nursing home. However, if her infection becomes severe, it is likely to take her life.

I was afraid you would say that.

ASK: It's not what any family member wants to hear. Given that, if the worst case scenario happened and she was going to die, do you think she would rather go to the hospital or be at home—I mean stay here at our nursing home.

We already decided not to send her to the hospital. From what I see on TV things are crazy there. The last time she went she got much worse and never bounced back from that. So keep her where she is and do the best for her there.

I can see that you want the best for her

Absolutely.

ASK: Let me put it another way. If she didn't have dementia and was her old self just for a moment. And she understood COVID and what would happen if it got bad. If she were sitting here with us, what would she say.?

Oh she would say, enough already. I'll stay here.
Just keep me comfortable.
...But I don't know.

It sounds to me like you know what she would say. But you're saying I don't know. Did I get that right?

Yes. We're not ready to lose her!

It's not the kind of decision anyone wants to make. It does sound like you two may have talked about this?

She told me when she was first diagnosed with dementia, like 10 years back, back then she was just a little forgetful, nothing big. We were driving to the park to walk the dog. She turned to me and said remember, when I can't do this anymore, it's time to let me go.

Pauses...Wow, thank you for telling me that.

I had kind of forgotten about that. Its funny—I can see her saying it to me.

Hmm. That kind of memory is a gift. Would it be ok to honor that?

Now it's clear to me. Let's keep at her at her home, right there. But she looks so uncomfortable, can't you do anything for her?

What did the nurse accomplish?

- Evoked the voice and wishes of the patient;
- Supported the son to honor those wishes;
- Together arrived at a decision to keep her in the nursing home and to make sure she is comfortable.

Treating Shortness of Breath

- If oxygen does not provide sufficient relief, the most effective therapy for dyspnea is low dose opioids, like morphine.
- In an older person, the starting dose is very low: Liquid morphine concentrate (Roxanol), 5mg/ml → give 2.5 mg or ½ ml under the tongue or in the cheek every 15 minutes until the respiratory rate comes down to about 20.
- Give the dose necessary to provide relief every 3 hours around the clock.

Agitation, Restlessness

- Recent literature shows not only that antipsychotic drugs like haloperidol increase mortality, they are no better than placebo in treating agitation or restlessness (delirium).
- If the morphine and the relief of dyspnea it provides is not adequate to provide relief of restlessness/agitation, add liquid oral lorazepam (Ativan), 5mg/5ml, 2.5mg or 2.5 ml under the tongue or in the cheek every hour until peaceful, repeat as needed every 3-4 hours.

What About Visitors?

- The main barrier to allowing visitors when patients are near the end of life is lack of PPE.
- If your facility has enough PPE to provide to family members of dying residents, and your policy permits it, they can visit.

Saying Goodbye

- When you need to talk a family member through saying goodbye to a patient who is in their last hours or minutes:
- I am [name], one of the [professionals] on the team. For most people, this is a tough situation. I'm here to walk you through it if you'd like.
- Offer the five things that matter to most people: We have the opportunity to make this time special. Here are five things you might want to say. Only use the ones that ring true for you.
 - Please forgive me
 - Thank you
 - I forgive you
 - I love you
- Validate what they want to say: I think that is a beautiful thing to say. If my [son] were saying that to me, I would feel so valued and so touched. I think she can hear you even if she can't say anything back. Go ahead, just say one thing at a time. Take your time.
- Expect emotion: I can see that she means a lot to you. Can you stay on the line a minute? I just want to check on how you're doing.

What did the Nurse Accomplish ?

- She gave the family the opportunity to say thank you; to express love; to give and seek forgiveness; and to say goodbye in time.
- This is a gift. Families that do not have this opportunity have a much higher risk of complicated grief and bereavement.

For Help

- Call hospice if the patient is near end of life.
- Call the local palliative care team.