

Family caregivers can help shape the outcomes for their loved ones—an ICU nurse explains their vital role

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The floor nurse had just told me that my new patient—let's call her Marie—would not stop screaming.

Marie landed in the [intensive care unit](#) where I am a bedside nurse because she was too agitated and needed more oxygen. We immediately tried to fit her with a more advanced oxygen mask, but the screaming continued and her oxygen level worsened. No matter how much I comforted her, it was not my hand she wanted to hold. She was screaming for her daughter, April, who was on her way.

April had been Marie's [caregiver](#) at home for the past few years after Marie was diagnosed with end-stage Alzheimer's. April is Marie's familiar face, her source of comfort when she gets disoriented. Now Marie had been admitted to the hospital for pneumonia, and April had not left her side.

As a seasoned bedside critical care nurse, I see firsthand the benefits that family caregivers bring to [patient care](#) in the hospital. I also witness the [emotional stress](#) that caregivers experience when their loved one comes to the ICU.

After years of helping families and physicians navigate the complicated course of an ICU hospital stay, I have some [advice for caregivers](#) to take with them.

Caregivers often battle anxiety and depression

From making [medical decisions](#) to advocating for their loved one, family caregivers have many important roles when their loved one is in the hospital. Their presence not only provides a sense of security, but also strongly influences [a patient's response to treatment](#).

For example, Marie refused to take walks during [physical therapy](#) until we found out from April that she felt safest in her pink New Balance shoes, which April brought to the hospital. April's unique knowledge of Marie's specific needs proved to be invaluable to guiding Marie's

treatment plan at the hospital.

Including the family in the patient's treatment plan, also known as family-centered care, can [help shorten a patient's hospital stay](#) and can even reduce hospital costs. However, caregivers carry heavy emotional burdens while supporting loved ones at the hospital.

In fact, [family caregivers](#) are at high risk of [developing long-term psychological health problems](#). Up to 70% of first-degree relatives of ICU survivors suffer from anxiety symptoms, [more than a third suffer from depression](#), and many can experience [symptoms of post-traumatic stress disorder](#), or PTSD.

There are ways to help ease this emotional burden, and most of them come down to consistent and open communication between the patient, their caregivers and the medical team.

But how should you, as the caregiver without much medical knowledge, communicate with hospital staff when your loved one can't speak for themselves?

Communication is critical

First, exchange contact information with the primary medical team, which may include a passcode for patient privacy. This will ensure that you receive the most updated information about the patient and will give you the peace of mind knowing that you can call at any hour of the day or night to receive updates on your loved one.

Second, let the medical team know what the patient is normally like at home, which can include the patient's medications, their baseline functional capabilities, any cultural or religious preferences, and their end-of-life wishes, just in case. With this information, the medical team

can develop a reasonable treatment plan specific to your loved one, avoid unnecessary and uncomfortable tests, and provide a better insight into their prognosis and recovery.

As you provide information about the patient at home, the medical team should be giving you updates about the patient's condition in the hospital. This is a good time for you [to keep a diary](#) to write down essential information and questions to ask them.

Knowing what to ask is essential to effective communication at the hospital. First, get yourself oriented to the hospital unit you are on: Ask about the visitation policy, unit phone number and even where the cafeteria and the bathrooms are.

Once familiar with your new environment, you may feel more at ease to truly be present for your loved one. Other important questions you can ask each day include:

- What is happening to my loved one?
- What is the plan for the next day?
- What will the treatment be like for my loved one?

These are good first questions for setting daily expectations for the patient's hospital stay. You can also find answers by participating in the patient's clinical rounds. Every day, the interdisciplinary medical team sees each patient to discuss updates and treatment plans, and answers questions for the patient and their family. Research has also shown that rounds [relieve anxiety and stress among family caregivers](#) due to the consistent daily communication and emotional support that they provide.

Nurses can be helpful

After clinical rounds, the interdisciplinary team of doctors and nurses

establishes a daily plan of care for your loved one, which will be carried out by your bedside nurse. The nurse will give the ordered medications, perform necessary clinical tasks and assess the patient for their response to the treatment. If you normally take care of the patient's basic needs at home, offering to help your nurse with feeding or bathing [may provide emotional reassurance](#) to you and your loved one.

Nurses are the most accessible resource you have when your loved one is in the hospital. They can provide [emotional support](#) and coping strategies during this stressful time and can act as a translator between you and the physicians.

Once you establish a good relationship with your [nurse](#) and the medical team, spend quality time with your loved one. Even when the patient isn't responsive, talk to them about familiar people in their life, FaceTime other family members, play their favorite music or TV show, and always remind them of the date and that they are in the hospital.

The importance of routines and familiarity

Since it's easy for patients to lose track of the normal day-night cycle, they can be at high risk of [ICU delirium](#), which is an acute and severe state of confusion. Preventing ICU delirium through reorientation and familiar faces can help prevent this serious complication and can even reduce their hospital stay.

Finally, one of the most important but often neglected task for you to do [is self-care](#).

Research advises caregivers to [tend to their own health and emotional needs](#) by eating regularly, getting adequate sleep and taking breaks from the hospital. You have been strong for others and can continue to do so, but only if you take care of yourself as well.

Most families that come to the hospital describe the support they received from the medical team [in a positive way](#). Your nurses and the rest of the medical team are all on your team, and we want the best possible outcome for your loved one.

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