On Caregiving: Advocating for a Loved One in the Hospital

When a loved one has been admitted to the hospital, chances are good that both you and the patient will be confronted with conflicting emotions. The patient may be struggling to adjust to what this means for quality of life, but be uncertain of what questions to ask the healthcare team. You might see this and try to seek clarification from the physician, but feel uncertain of what questions to ask. If you can think of a question to ask, you could likely face a whirlwind of new terminology. Healthcare providers may move quickly in and out of the room, order new tests, or begin administering medication without consulting you. This can leave both you and the patient feeling bewildered. One way to take control of this uncomfortable situation is to learn to act as a patient advocate.

**Who can be a patient advocate?**

A patient advocate is usually either a close friend of family member who is willing and able to be present during appointments, tests, and procedures. Because hospitals move on their own time, patient advocates may need to be able to set aside large amounts of time, particularly during a crisis. It’s important to keep work and family responsibilities in mind so you can be honest with the patient about your ability to be present. Remember that if you cannot act as a patient advocate, you can still offer support and presence in other ways.

A patient advocate does not need to have a healthcare background, but it can help if you have either some familiarity with medicine. However, willingness to learn is the only real requirement, and this can be easy to do with the plentitude of information available on the Internet. [John Hopkins Medical Center](https://www.hopkinsmedicine.org/johns_hopkins_bayview/patient_visitor_amenities/community_health_library/finding_reliable_health_information_online.html) offers strategies and resources for finding reliable health information online.

Patient advocates have three key areas where they can most offer help: facilitating communication, ensuring safety, and facilitating recovery.

**What do patient advocates do?**

An advocate’s first responsibility is to **facilitate communication** between the patient and the care team. If the patient is unable to speak or disoriented, you may need to discuss their symptoms with the care team. Provide as much information as you can, including timing and severity of symptoms. Whenever possible, have access to the patient’s medical history, preferably in electronic format. If the care team has access to comprehensive information they will be able to more accurately diagnose and treat the patient.

If possible, discuss with the patient ahead of time the questions they would like you to ask healthcare providers. Some possible questions to consider include:

* Can you describe the procedure for me?
* Why do you recommend that I have this procedure?
* What options exist for pain relief?
* What does the recovery time look like?
* What are some likely complications that I may encounter?
* How long should I expect to be in the hospital for?
* What are the costs of this procedure?

As a patient advocate, you may have to be assertive. If a physician’s answer feels unsatisfying, you have the right to ask follow-up questions. Periodically consult with the patient to see if they are feeling comfortable with the care team’s response, or if more questions are necessary.

Checking in with the patient can also help you be aware of how much or little the patient may likely to speak. Would the patient like to direct the conversation while you take notes or add information as needed? Or would the patient prefer to sit back and take in the answers while you speak with the physician? The patient’s level of involvement may change before and during the consultation.

During hospitalization, an advocate can help **ensure patient safety.** You can do this in several ways. Whenever possible, you should have access to a list of the patient’s current medications and allergies. While the hospital should keep this on file, you can help avoid errors by confirming information with the care team.

Whenever hospital staff arrive to administer treatments or perform tests, your presence can help them avoid accidents. It’s a good idea to be certain that healthcare providers either wash or glove their hands before treating your loved one. If a member of the care team is administering medication, you can help by asking several routine questions that confirm what the medication and dosage is, what it is for, and what side effects you might anticipate.

If the patient is being taken for tests, confirm with the care team that they are taking the right patient, and ask what this test is for. Will this test offer more information to assist with treatment? Will it clarify an uncertain diagnosis? If a test seems repetitive or unnecessary, ask that the care team wait until a physician explains the rationale behind ordering it.

When the patient is ready to be discharged, the primary physician should arrive for a brief meeting with you and the patient. At this time, you should confirm what the follow-up plan is in the next few weeks. If any follow-up visits are necessary, they should be scheduled at this time. Pharmacy staff should be consulted to discuss what medications the patient will leave with, and which ones will be discontinued. If there is any need for wound or surgical site care, you can ask the healthcare team to demonstrate this procedure for you. They should also provide written instructions to take home.

It can also be a good idea to ask what complications may occur. What are some signs of infections or worsening that will necessitate medical attention? Knowing this can help relieve post-hospitalization stress for both you and the patient.

With these practices in place, you can ease the stress and uncertainty of a hospital stay for both you and the patient. Acting as an advocate allows you ensure that the healthcare team can do their best work in assisting the patient. Acting as an advocate offers peace of mind and is an invaluable gift to those around you. Since you will be present, navigating complicated bureaucracy and procedures, your loved one can devote all their energy and attention to recovery.