**DRAFT Background Information Patients Rights Issues for New York StateWIde Senior Action Council Workgroup on Patients Rights Telephone Teach In on 12/10/19)**

During 2019 a workgroup of Albany and Saratoga Chapter members have been identifying problems that older persons and caregivers experience with hospitals and have also suggested several solutions to these problems. Policy or legislative changes may be needed to address several of these concerns.

During the coming year StateWide's Policy Committee will consider suggestions that come out of this work to help promote a better system of health care in New York. We will be holding a series of conference calls and forums to discuss these issues and promote system wide solutions.

For further information, comments or suggestions you may email:

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**PROBLEMS WITH THE CURRENT SYSTEM:**

**1. Failure to include caregiver input in patient records.** Opportunities for patients and their families to have meaningful participation decisions surrounding patient care are often limited. Often critical input from the caregivers is not included in the record and thus not available for consideration by reviewing agencies when a request is made to Livanta or the Department of Health.

2. **Patients are not fully made aware of the treatment and care they will receive**. Individuals seeking medical help in hospital settings are often unaware of the basic care, conditions, problems, and scenarios they are likely to face once admitted.

3. **The Patient Advocacy Departments in Many Hospitals are Ineffective.** Medical facilities often do not respond to patient advocacy matters in an effective manner. There are significant limitations. For example:

What are the chances of seeing a patient advocate at a critical time when the problem occurs on a weekend? How can patients and families respond when the hospital’s advocacy staff never appears? What happens when an advocacy department fails to follow-up on a request for a full review of a medical issue?

4. **Hospitals have little responsibility to share the information that might appear in a formal review.** The present system for information sharing during an internal review of a complaint does not allow ready access to patient records. It is very difficult to learn what considerations or discussions or corrective actions were taken as a result of a complaint to the hospital or review agency. It appears to support hospital practices which delay, deflect, deny, disavow, and misrepresent amount of effort spent on patient advocacy concerns.

**5. Doctors, Hospitals and Health Providers Do Not Communicate Well With Families After Poor Outcomes.** Concerns about blame or liability may prohibit providers from consoling families after poor outcomes or death yet this is exactly the time they should be connecting with families.

**6. Information about hospital complaints is not readily available to patients and families.** Data on patterns of poor care can be extremely helpful in guiding patients and caregivers as well as providing incentives to hospitals to address chronic problems with patient care.

**DRAFT PROPOSALS FOR IMPROVING HOSPITAL COMMUNICATION WITH PATIENTS AND CAREGIVERS**

1. **Patient Education** *The New York State Department of Health should require health providers to inform patients to help prepare them for a hospital stay and/or an Emergency Room visit.*

Patients requiring hospital stays need to be given accurate information about the setting they will enter by the referring party [specialist, primary care practice, urgent care, PA, etc.] and the admissions department. A Patient Information Card should be provided whenever a referral for hospital treatment is made. This information should be a viewed as an ethical and professional obligation to the patient. The information should a include details on: what professionals will be treating the patient during their stay and during any post operative period or recovery period in the hospital and who they can talk to if they have a question or concern during the hospital visit. This should be mandated information, regardless what the point of patient referral may be.

2. **Access to a Patient Advocate in Each Hospital***Each hospital should have a clearly identified patient advocacy department to deal with patient and caregiver concerns. The contact information for this department should be provided upon admission.*

This position should be more than a patient navigator or adjunct to the billing department. The responsibilities of this staff person must include enforcement of the patient bill of rights. Caregivers should be able to talk to this designated contact when they are have difficulty communicating with hospital medical staff or if such staff are unavailable.

Midnight or weekend discharges should get special attention to make sure that families have access to a patient advocate.

There should be state standards for uniformity across hospitals regarding Patient Advocate titles, functions, staffing designations, and protocols for such offices. No patient should be confused as to what their treatment and recovery issues plans are.

*3.* ***Communications with Hospitals*** *Accurate information about patient status must be made available to patients and their caregivers in a timely manner and hospitals must be required to identify a point person that patients can contact for this information.*

Successful health care rests on the ability of patients, their families, and advocates to have effective communication with hospital and medical staff. Caregivers can provide critical information about patient health history or report changes that they have observed and about which the provider may not be aware of or detect.

The responsibilities of hospitals related to such communication are stated in federal regulation A-0130 (Rev.75, Issued: 12-02-11, Effective: 12-02-11, Implementation: 12-02-11) §482.13(b)(1) which states: The patient has the right to participate in the development and implementation of his or her plan of care.

Interpretive Guidelines §482.13(b)(1) requires the hospital to actively include the patient in the development, implementation and revision of his/her plan of care. It requires the hospital to plan the patient’s care, with patient participation, to meet the patient’s psychological and medical needs. The patient’s (or patient’s representatives, as allowed by State law) right to participate in the development and implementation of his or her plan of care includes at a minimum, the right to: participate in the development and implementation of his/her inpatient treatment/care plan, outpatient treatment/care plan, participate in the development and implementation of his/her discharge plan, and participate in the development and implementation of his/her pain management plan.

4. **Caregiver Input Should be included in Patient Records**. S*tandards related to the inclusion of caregiver input into medical records should be established so that all hospitals to function in the same manner. Information provided by patients and caregivers about a patient should be entered into the hospital electronic medical records including:*

* *Requests for case reviews during a hospital stay as well as after discharge. The patient or representative should have an opportunity to read the findings generated through this process.*
* *Requests to meet with medical staff concerning diagnosis or medical prescriptions.*
* *Quality of care requests to the Patient Advocacy Department.*
* *Requests for the names of doctors and nurses responsible for the patient. This should also include a time schedule as to days and times they are available.*
* *The hospitals should include responses to these requests in their EMR data base and patient portal systems. Electronic platforms must allow meaningful dialogue to take place among the important stakeholders in a patient’s stay. Much of this type of technology is already in place in medical practices and hospital settings.*

4. **Communication After Hospital Visits** *It is very important for health professionals to have discussions with the families of patients when there are bad outcomes or death. Especially if they have been caring for them for many years. Physicians need to be encouraged to follow up with the family to express their understanding or condolence. StateWide should work with the Geriatric Education Centers and the American College of Physicians and other appropriate groups to educate physicians about this important part of their practice of care.*

5. **Provide the Public with Transparency Regarding Hospital Complaints** *The State Should Make the Results of Actions on Complaints Made by Patients and Families to DOH Public.*Information about systems problems is critical to improving our system of care. This information should be made available to the public and include data regarding:

- the number and types of complaints received on each hospital

- the action or inaction taken by DoH

-corrective actions required

- fines or penalties implemented

6. **Enforce Patients Rights and Caregivers Rights Through the Hospital Survey Process and the State System for Investigation of Complaints** *DoH should regularly share information about the types of complaints that have been made about hospitals and the status or resolution of these complaints in easy to understand format.*

Federal conditions of participation clearly define the rights of patients and their representatives to: obtain prompt resolution of any grievances, access information contained in clinical records in a reasonable timeframe, and participate in the development and implementation of care plans.

Under New York's current hospital complaint system, individual cases are not all investigated. The Department of Health and Livanta look only at clinical outcomes against medical best practice guidelines. Poor communication between the hospital and patients and/or their representatives is not addressed in the complaint process and no corrective action is mandated. Complaints that are not deemed outside of medical protocols or guidelines are not forwarded to hospitals and this leads to a permissive system provides inadequate responsiveness and allows similar problems to continue unaddressed. This is unacceptable.

StateWide will work with the Department of Health and the legislative Health Committees to review the current system of addressing complaints about hospitals and develop public reports on the status of complaint resolution.