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HUMAN RIGHTS AUTHORITY - PEORIA REGION
REPORT OF FINDINGS

Case # 13-090-9003
Sharon Healthcare Facilities

INTRODUCTION

The Human Rights Authority (HRA) opened an investigation after receiving complaints of possible rights violations at one of the Sharon Healthcare's facilities in Peoria. The allegations were as follows:

1. The facility did not pursue a guardian's request for medical intervention in a timely manner.
2. The facility did not follow a physician's orders regarding surgical preparation.

If found substantiated, the allegations would violate the Skilled Nursing and Intermediate Care Facilities Code (77 ILCS 300), the Nursing Home Care Act (210 ILCS 45), the Probate Act of 1975 (755 ILCS 5/1-1 et seq.), and the Health Care Surrogate Act (755 ILCS 40).

The facility Sharon Elms is a skilled nursing facility that has 98 beds and employs 100 staff members including registered nurses (RNs), licensed practical nurses (LPNs), and certified nursing assistants (CNAs). The facility serves individuals from Illinois and from other states.

This review includes interviews with Sharon Elms representatives, and a review of program policies as well as specific records with authorization from a resident's plenary guardian of the person.

Complaint Statement

The allegations state that a resident in one of Sharon Healthcare's facilities was diagnosed with laryngeal cancer. The physicians involved wanted to treat the cancer without surgery, but the resident refused treatment. The physicians then decided on surgery for the cancer which the resident also refused. Reportedly, because of the resident's mental condition, the resident denied even having the cancer and did not want treatment for the disease. The resident's guardian

requested to proceed with the treatment but the physician at the facility disagreed with the decision on an ethical level because the resident did not want the treatment. The complaint states that the facility said they would proceed and assist with the surgery, but actually did not assist in pursuing the guardian's request for medical intervention in a timely manner.

The complaint also states that the resident was given an order for no food or water by mouth (NPO) after midnight on the night before the surgery, but on the morning of the surgery, staff stated that the resident consumed soda, which forced the surgery to be cancelled.

FINDINGS

Interview with staff (10/23/2012)

The staff explained that the resident was at Sharon Pines but was moved to Sharon Elms because he recieved a tracheotomy. Because Sharon Pines could not handle a resident with a tracheotomy, he was admitted on 4/27/12 to Sharon Elms and, according to the staff, all allegations concern Sharon Elms. Staff explained that the resident had a mental health diagnosis of schizoeffective disorder. Staff said that after the resident recieved the diagnosis of cancer and the tracheotomy, he was given two treatment options that he refused. They attempted to schedule the resident for chemotherapy but he refused and never received cancer treatments. Staff said that it was explained to the resident that certain treatment procedures would make him unable to speak or to eat, that he could not talk after the tracheotomy but he could whisper and write to communicate. Staff said that at some point, the resident's guardian talked to the physician and decided to proceed with a laryngectomy, and without it, death was certain. Sharon Elms' staff talked to the resident on numerous occasions explaining all the consequences of having surgery and the resident did not want surgery. The staff reported that the resident's guardian stated that the resident was not competent to make decisions. The staff expressed that the facility does not agree with the guardian's view on the patient's competence. They believed that a court found the resident in need of a guardian, but because of the changes in medications and other factors, the resident had improved and could make independent decisions. Staff explained that the court decision was long ago and the facility believed the resident had a higher level of competence than before. The staff also expressed that the facility was caught in the middle of the situation regarding surgery. They explained that there was an ethical aspect to the surgery and the main question dealt with the resident's right to make his own decisions. Staff stated that at one point, the resident agreed to have the surgery. They said the facility recieved the orders for the surgery and on the morning of the surgery, the resident changed his mind, which is when the resident purchased and drank soda. The guardian arrived at the facility the morning of the surgery and that was when a nurse told the guardian that the resident was refusing surgery and drank soda.

Staff explained that the facility consulted its attorney who said they could not force the resident to have the surgery. Staff also said that they called the Illinois Department of Public Health for advice who unofficially said to follow their attorney's advice. Staff stated that they met with the guardian and asked if the guardian could take the situation to court because without a court order they could not physically force a resident into treatment, but the guardian refused. Staff explained that the facility physician is the resident's primary physician and the resident refused to see any others. Basically, the facility only assists with the treatment and follows the

physician's orders. If residents refuse, then staff reports the refusals to the doctor, family member, etc. The staff explained that they could not physically or chemically force the resident to do anything against his will. In the facility's opinion, they wanted the resident to recieve treatment if *he* wanted it.

The facility said they spoke with the surgeon prior to the laryngectomy and explained that the resident may not follow through with the surgery. After the resident refused, the surgeon sent a letter stating he would no longer see the resident as a patient. The staff said that the Sharon Healthcare physician tried talking to the resident about the surgery and informing him that he could die without it; still, he refused. Staff stated that after the sugery was cancelled, the resident's guardian spoke with him about treatment and was told he did not want surgery.

Staff explained that there was no evaluation to determine the resident's decisional capacity for treatment. Staff explained that in dealing with the resident on a daily basis, they felt he clearly understood the ramifications of not being treated for the cancer, that they never questioned his understanding of the situation, and that his charts reflected such. According to staff, the resident still stated he would not have the surgery.

We were told that the resident had no hallucinations with the schizoeffective disorder. Staff said that the resident had friends in another facility, he signed out of the facility and he signed back in, etc. Staff explained that, prior to the cancer diagnosis, the resident usually took care of himself. Staff said that the resident stayed at Sharon Pines for several years; the Pines is a facility that primarily serves individuals with mental health needs.

According to the staff, the resident only had one sip of soda on the morning of the surgery which was not enough to cancel the surgery. They said that the guardian was told that the resident drank some soda and then she left without speaking with the resident, and he was still cleared for surgery on that day. Staff explained that they have a process for residents who are NPO (Nil Per Os or nothing by mouth), such as taking water pitchers out of their rooms. The physician's orders stated the resident could have sips of water with morning medication. The majority of residents are not ambulatory, so they would not even have access to vending machines or money because of their physical situations. There are approximately 10 who are self sufficient including the resident involved in this complaint. Staff said that the resident usually got up early and if he had money, he bought a soda or would sometimes have a cup of coffee before breakfast.

It was explained to the HRA that the resident recieved a tracheotomy because he was not in a condition to indicate his agreement or disagreement with the procedure, so the resident's guardian approved the procedure. Staff said that they do not believe the onsite physician had a specific point of view about the surgery. Staff believes that the physician only presented facts with regard to the surgery and prognosis.

The staff reported that there are previous notes regarding the resident's capacity to understand treatment from a hospital. At one point the resident told his guardian that he did not have cancer, a comment about which they think the guardian became fixated. The staff said that they never heard the resident say he did not have cancer.

The staff said that there is no written policy or procedure for surgical orders; they just follow physician's orders. If the resident is scheduled for surgery, and the resident changes his/her mind, staff alerts the physicians and others who would need to know. If the surgery is cancelled because the resident changes his/her mind, it is then up to the parties involved to reschedule. Staff said that this process is not documented, just a standard procedure.

FINDINGS (Including record review, mandates, and conclusion)

The HRA reviewed policy and records pertinent to the allegations stated in this report. The HRA reviewed two court orders which indicate that the resident was legally adjudicated as disabled in 1999 and has had guardians since then.

The HRA also reviewed a medical history and physical examination dated 7/6/2010 that stated the resident has had a long history of schizoaffective disorder. A record of death for the resident dated 10/28/12 stated that the individual died on that day from Laryngeal Carcenoma Stage 3.

A facility policy statement that applies to both allegations reads "It is the Policy of Sharon Healthcare Elms to have and follow a written program of medical services which stands for the following: the Philosophy of care and policies and procedures to implement it; the structure and function of the medical advisory committee, if the facility has one; the health services provided; arrangements for transfer when medically indicated; and procedure for securing the cooperation of residents' personal physicians. The medical program shall be approved in writing and renewed annually." The HRA found no specific policy on medical care or guardian involvement.

Complaint #1 - The facility did not pursue a guardian's request for medical intervention in a timely manner.

The HRA reviewed a Summary and Physician's Progress Note dated 6/6/12 stating that the physician spoke with the resident about the Laryngeal Cancer and procedures and that the resident did not want treatment and understood the consequences. Another physician progress note dated 6/27/12 stated that the resident was to have a laryngectomy on that day but refused to go to the surgery. There is also another note on 7/11/12 that indicated the physician spoke with the resident's guardian and believed the resident understood the situation. This was not documented in a formal decisional capacity statement. The HRA reviewed two more instances in the physician's progress notes where it was mentioned that the resident was refusing surgery.

The HRA also reviewed nurses' notes regarding the resident. Notes pertinent to the case read as follows:

- On 5/9/12 the resident refused to go to a radiology appointment and asked to speak with his physician. The resident spoke with the physician who "assured the resident that he needed to keep his appt. Resident decided to go."
- On 5/10/12 at 1:30pm, "Res refusing to go to radiation appt. States 'I don't have cancer and I don't have the need to go.' Reminded res of conversation with [physician] re: fact that even though Drs. say they have got all the cancer, the need to follow-up with chems and radiation exists because no one is 100% sure of anything. Res recalled conversation and states 'I don't have cancer. I'm not going to go to radiation.'"
- On 5/29/12, "[Guardian] is in the nsg office at this time stating res is scheduled for total laryngectomy on June 27th. When questioned about res refusal, [guardian] states she is working with oncologists and attorneys and 'res will not be able to refuse with her acting as his surrogate.' States 'that's why she is appointed over mentally ill pts to act on their behalf as they cannot understand total picture and she will not sit back and watch him suffocate.' Requests H & P [History and Physical] for clearance from [physician] and states 'if [physician] will not clear res for surgery she will find a dr. who will clear res and she will speak with facility owners.'"
- In another passage on 6/1/12 it reads "Spoke with [physician] re: need for res clearance for surgery. States will complete H & P and base results on that for clearance."
- On 6/6/12, "[Physician] here seeing resident and discussed cancer treatments. Dr. explain what a total Laryngectomy was and he would not be able to eat and would have to have G-tube placement. [Resident] stated No, I will not have any surg or G-Tube. Dr. again ask if he refuse surg would he take chemotherapy and radiation. [Resident] stated he would not take that therapy. Dr. stated it was 'possible' if he took therapy he could continue to eat. Ans. No. Dr. states if he did not do the surg or therapy he would die - Stated then I'll die because I'm not doing it, I want to talk to my attorney." The note states that the physician asks once more if the resident understood the ramifications and the resident said "I understand exactly what you said, so I guess I'll die."
- On 6/13/12 the physician performed a physical and decided to leave him on medication for pneumonia, he called the surgeon and said he would not clear the resident unless he was seen by "Pulmonary" first and the surgeon agreed. In that same passage the resident agreed to the surgery.
- On 6/20/12, the resident was requesting to move back to Sharon Pines, and the resident was reminded that he could not possibly move back because he refused surgery. The resident's guardian was notified and made a request that the surgeon order sedation prior to surgery. The surgeon's office was notified and they stated that pre-operation medication would be sent. The guardian also said there was a possibility of having Emergency Response Service (ERS) as a stand-by if the resident resists. A later note, dated 6/25/12 states ERS could not offer assistance with the situation and they would contact the guardian. No reason was provided as to why they could not assist.
- On 6/22/12, Valium was received and the prescription orders of when to take were copied into the nursing notes because the prescription was illegible.
- On 6/26/12 the guardian called to confirm the surgery and asked that the facility attempt to do everything possible to get the resident in the cab and, according to the note the "Writer informed [guardian] that facility can only encourage res to go in cab but that we cannot legally force him to get in a cab."

- On 6/26/12 a different nurse writes, "During the discussion I told her [guardian] he was still saying he didn't want to go, he didn't want the surgery. She went into details of him being found incompetent by a judge due to severe MI diagnosis years ago, so a guardian was appointed. I explained I would and have tried to follow all directions with instructions given but if the res. absolutely refused to have the surgery and refused to and into the cab coming for him in the morning we could not physically force him to go."
- The notes on 6/27/12 indicated that the resident did not leave for the surgery in the cab.
- On 7/11/12, the guardian called to ask if surgery had been rescheduled or if the physician had obtained a surgeon. The note states that the physician "explained to [guardian] that [resident] does not want surg. I [dr] have spoken to resident many X's and he cont. to refuse. Does he know he has Cancer 'Yes'. I [dr] believe resident understands and chooses no intervention at this X. Ethically and morally I cannot force resident to have this surg."

The HRA reviewed the resident's care plan, dated 5/12/12. In the care plan, under health conditions, it stated that the resident had "Potential for swallowing/breathing difficulties due to laryngeal cancer." In that section, it mentioned that the resident refused follow-up appointments with radiologists and oncologists, g-tube placement and a transfer to the hospital on the 6/27. In the care plan, there was no dictation of the guardian's directives or any plan in place to carry out the guardian's wishes. The only written statement reads "Consultation with house physician regarding anticipated surgery, consequences of refusal, etc. Keep guardian informed of res. Refusal for plan of care." In the nursing and social work notes, there was an indication that the guardian had the individual screened for placement at other nursing homes. This also did not appear in the care plan.

The Probate Act of 1975 reads "(b) Every health care provider and other person (reliant) has the right to rely on any decision or direction made by the guardian, standby guardian, or short-term guardian that is not clearly contrary to the law, to the same extent and with the same effect as though the decision or direction had been made or given by the ward. Any person dealing with the guardian, standby guardian, or short-term guardian may presume in the absence of actual knowledge to the contrary that the acts of the guardian, standby guardian, or short-term guardian conform to the provisions of the law. A reliant shall not be protected if the reliant has actual knowledge that the guardian, standby guardian, or short-term guardian is not entitled to act or that any particular action or inaction is contrary to the provisions of the law" (755 ILCS 5/11a-23).

The Probate Act of 1975 also reads as follows:

"(a) To the extent ordered by the court and under the direction of the court, the guardian of the person shall…make provision for [the ward's] support, care, comfort, health, education and maintenance, and professional services as are appropriate….

(d) **A guardian acting as a surrogate decision maker under the Health Care Surrogate Act … shall have all the rights of a surrogate under that Act without court order including the right to make medical treatment decisions such as decisions to forgo or withdraw life-sustaining treatment. Any decisions by the guardian to forgo or withdraw life-sustaining treatment that are not authorized under the Health Care Surrogate Act shall**

require a court order [emphasis added]

(e) Decisions made by a guardian on behalf of a ward shall be made in accordance with the following standards for decision making. Decisions made by a guardian on behalf of a ward may be made by conforming as closely as possible to what the ward, if competent, would have done or intended under the circumstances, taking into account evidence that includes, but is not limited to, the ward's personal, philosophical, religious and moral beliefs, and ethical values relative to the decision to be made by the guardian. Where possible, the guardian shall determine how the ward would have made a decision based on the ward's previously expressed preferences, and make decisions in accordance with the preferences of the ward. If the ward's wishes are unknown and remain unknown after reasonable efforts to discern them, the decision shall be made on the basis of the ward's best interests as determined by the guardian. In determining the ward's best interests, the guardian shall weigh the reason for and nature of the proposed action, the benefit or necessity of the action, the possible risks and other consequences of the proposed action, and any available alternatives and their risks, consequences and benefits, and shall take into account any other information, including the views of family and friends, that the guardian believes the ward would have considered if able to act for herself or himself" (755 ILCS 5/11a-17).

The Probate Act also reads "Notice of right to seek modification. At the time of the appointment of a guardian the court shall inform the ward of his right under Section 11a-20 to petition for termination of adjudication of disability, revocation of the letters of guardianship of the estate or person, or both, or modification of the duties of the guardian and shall give the ward a written statement explaining this right and the procedures for petitioning the court" (755 ILCS 5/11a-19) and "Termination of adjudication of disability--revocation of letters--modification. (a) Upon the filing of a petition by or on behalf of a disabled person or on its own motion, the court may terminate the adjudication of disability of the ward, revoke the letters of guardianship of the estate or person, or both, or modify the duties of the guardian if the ward's capacity to perform the tasks necessary for the care of his person or the management of his estate has been demonstrated by clear and convincing evidence. A report or testimony by a licensed physician is not a prerequisite for termination, revocation or modification of a guardianship order" (755 ILCS 5/11a-20).

Regulations from the Skilled Nursing and Intermediate Care Facilities Code require the following:

"a) The facility shall have written policies and procedures, governing all services provided by the facility which shall be formulated by a Resident Care Policy Committee consisting of at least the administrator, the advisory physician or the medical advisory committee and representatives of nursing and other services in the facility ….

c) These written policies shall include, at a minimum the following provisions … 2) Resident care services including physician services, emergency services, personal care and nursing services, restorative services, activity services, pharmaceutical services, dietary services, social services, clinical records, dental services, and diagnostic service (including laboratory and x-ray). (B)" (77 Il Admin Code 300.610).

Section 300.1010 (f) of the Skilled Nursing and Intermediate Care Facilities Code states that "Physician treatment plans, orders and similar documentation shall have an original written signature of the physician. A stamp signature, with or without initials, is not sufficient." Sections 300.1210 (d) (2) and 300.3220 (f) both require that physician orders be followed.

The Skilled and Intermediate Care Facilities Code addresses life-sustaining treatment in Section 300.1035 and states that every facility shall have a policy related to life-sustaining treatment that covers livings wills and powers of attorney, do not resuscitate orders, staff responsibility related to life sustaining treatment and procedures for staff education. This section of the Code further requires the following:

"d) Any decision made by a resident, an agent or a surrogate…must be recorded in the resident's medical record. Any subsequent changes or modifications must also be recorded in the medical record.

e) The facility shall honor all decisions made by a resident, an agent, or a surrogate…or will transfer care….

f) The resident, agent, or surrogate may change his or her decision regarding life-sustaining treatment by notifying the treating facility of this decision change orally or in writing in accordance with State law.

g) The physician shall confirm the resident's choice by writing appropriate orders in the patient record or will transfer care…."

The Nursing Home Care Act states that "A facility, with the participation of the resident and the resident's guardian or representative, as applicable, must develop and implement a comprehensive care plan for each resident that includes measurable objectives and timetables to meet the resident's medical, nursing, and mental and psychosocial needs that are identified in the resident's comprehensive assessment, which allow the resident to attain or maintain the highest practicable level of independent functioning, and provide for discharge planning to the least restrictive setting based on the resident's care needs. The assessment shall be developed with the active participation of the resident and the resident's guardian or representative, as applicable" (210 ILCS 45/3-202.2a). The Act further states that a resident has the right to refuse treatment: "Every resident shall be permitted to refuse medical treatment and to know the consequences of such action, unless such refusal would be harmful to the health and safety of others and such harm is documented by a physician in the resident's clinical record." (210 ILCS 45/2-104(c) of the Act)

The Health Care Surrogate Act (755 ILCS 40) provides guidance on medical decision-making, decisional capacity and surrogate decision making. The Health Care Surrogate Act "is intended to define the circumstances under which private decisions by patients with decisional capacity and by surrogate decision makers on behalf of patients lacking decisional capacity to make medical treatment decisions or to terminate life-sustaining treatment may be made without judicial involvement of any kind." (755 ILCS 40/5) The Act "applies to patients who lack

decisional capacity or who have a qualifying condition [terminal condition, permanent unconsciousness, incurable or irreversible condition]…The Act does apply to patients without a qualifying condition. If a patient is an adult with decisional capacity, then the right to refuse medical treatment or life-sustaining treatment does not require the presence of a qualifying condition." (755 ILCS 40/15) The Act defines decisional capacity as "…the ability to understand and appreciate the nature and consequences of a decision regarding medical treatment or forgoing life-sustaining treatment and the ability to reach and communicate an informed decision in the matter as determined by the attending physician." (755 ILCS 40/10) Furthermore, the Act's definition of health care facility includes nursing homes and long term care facilities (755 ILCS 40/10).

In Section 40/55, the Health Care Surrogate Act preserves existing rights as follows: "The provisions of this Act are cumulative with existing law regarding an individual's right to consent or refuse to consent to medical treatment. The provisions of this Act shall not impair any existing rights or responsibilities that a health care provider, a patient, including a minor or a patient lacking decisional capacity, or a patient's family may have in regard to the withholding or withdrawal of life-sustaining treatment, including any rights to seek judicial review of decisions regarding life-sustaining treatment under the common law or statutes of this State to the extent they are not inconsistent with the provisions of this Act."

The Act also stipulates that the health care provider "shall have the right to rely on any decision or direction by the surrogate decision maker…that is not clearly contrary to this Act, to the same extent and with the same effect as though the decision or direction had been made or given by a patient with decisional capacity."

With regard to medical decision making, the Act states that "Decisions concerning medical treatment on behalf of a patient without decisional capacity are lawful, without resort to the courts or legal process, if the patient does not have a qualifying condition and if decisions are made in accordance with one of the following paragraphs in this subsection and otherwise meet the requirements of this Act: Decisions concerning medical treatment on behalf of [an] …adult who lacks decisional capacity may be made by a surrogate decision maker…in consultation with the attending physician, in order of priority in Section 25 [guardian of person being the first priority in the Section 25 list] with the exception that **decisions to forgo life-sustaining treatment may be made only when a patient has a qualifying condition.** [emphasis added] A surrogate decision maker shall make decisions for the patient conforming as closely as possible to what the patient would have done or intended under the circumstances, taking into account evidence that includes, but is not limited to, the patient's personal philosophical, religions and moral beliefs and ethical values relative to the purpose of life, sickness, medical procedures, suffering and death….If the adult patient's wishes are unknown and remain unknown after reasonable efforts to discern them…the decision shall be made on the basis of the patient's best interests as determined by the surrogate decision maker. In determining the patient's best interests, the surrogate shall weigh the burdens on and benefits to the patient of the treatment against the burdens and benefits of that treatment and shall take into account any other information, including the views of family and friends , that the surrogate decision maker believes that patient would have considered if able to act for herself or himself….With respect to a patient, a diagnosis of mental illness or an intellectual disability, of itself, is not a bar to a

determination of decisional capacity. **A determination that an adult patient lacks decisional capacity shall be made by the attending physician to a reasonable degree of medical certainty. The determination shall be in writing in the patient's medical record and shall set forth the attending physician's opinion regarding the cause, nature and duration of the patient's lack of decisional capacity. Before implementation of a decision by a surrogate decision maker to forgo life-sustaining treatment, at least one other qualified physician must concur in the determination than an adult patient lacks decisional capacity**. **[emphasis added]** The concurring determination shall be made in writing in the patient's medical record after personal examination of the patient. The attending physician shall inform the patient that it has been determined that the patient lacks decisional capacity and that a surrogate decision maker will be making life sustaining treatment decisions on behalf of the patient….A surrogate decision maker acting on behalf of the patient shall express decisions to forgo life-sustaining treatment to the attending physician and one adult witness who is at least 18 years of age. This decision and the substance of any known discussion before making the decision shall be documented by the attending physician in the patient's medical record and signed by the witness…..Once the provisions of this Act are complied with, the attending physician shall thereafter promptly implement the decision to forgo life-sustaining treatment on behalf of the patient unless he or she believes that the surrogate decision maker is not acting in accordance with his or her responsibilities under this Act, or is unable to do so for reasons of conscience or other personal views or beliefs. (755 ILCS 40/20)

The Health Care Surrogate Act defines decisional capacity in Section 40/10 as "…the ability to understand and appreciate the nature and consequences of a decision regarding medical treatment or forgoing life-sustaining treatment and the ability to reach and communicate an informed decision in the matter as determined by the attending physician." The forgoing of life-sustaining treatment "…means to withhold, withdraw or terminate all or any portion of life-sustaining treatment with knowledge that the patient's death is likely to result." And, a qualifying condition includes one or more of the following conditions as certified by the attending physician and another qualified physician: terminal condition; permanent unconsciousness, and/or incurable or irreversible condition.

Complaint #1 - Conclusion

It is beyond the scope of the HRA to determine whether or not the resident in this case had decisional capacity in terms of the Health Care Surrogate Act provisions and it is also beyond the HRA's scope to analyze the guardian's standards for decision making (substituted judgment versus best interest standards). The HRA's role is to determine whether or not a resident's rights were violated by the facility with regard to facilitating the guardian's involvement, providing timely medical intervention and ensuring that the provisions of existing mandates are met, including provisions of the Health Care Surrogate Act, the Probate Act of 1975 and the Nursing Home Care Act. In this case, an individual had been adjudicated by the Probate Court as legally disabled and in need of a guardian; a guardian was subsequently appointed and served in that capacity for many years. The Probate Act states that the guardian's role is to procure and make arrangements for the care of a ward, including health care. The Probate Act requires that a guardian's decisions are to be made using substituted judgment (what

the ward would have chosen) first and then using best interest standards if substituted judgment could not be applied. At the same time, the Nursing Home Care Act recognizes the right of a nursing home resident to refuse treatment. Nursing home regulations require a policy on advance directives, the documentation of related decisions and the transfer of care if the physician cannot abide by the decisions made. The Health Care Surrogate Act which applies to all nursing homes, including Sharon Elms, allows for surrogate decision making without court involvement. The Health Care Surrogate Act also stipulates that decisional capacity is to be determined in writing by the physician when considering surrogate decision making. The guardian in this case argued in favor of surgery for the resident in spite of the resident's voiced refusals making the argument that the resident did not fully understand the repercussions of refusing the surgery. The facility argued that the resident refused the surgery and they could not force him to have it. They also argued that the resident understood the surgery and repercussions. The record indicated at different points in time both the resident's refusal and, on at least one occasion, agreement with the surgery. On 07-11-12, the physician made a clear statement regarding the resident's understanding of the surgery and his prognosis without it. The HRA commends the facility and the physician for pursuing and then documenting the resident's wishes and understanding of the surgery. However, there is no concurring physician's statement of the resident's decisional capacity. Given the likelihood of death without the timely intervention of surgery, the situation represented the forgoing of life-sustaining treatment as described in the Health Care Surrogate Act. Thus, a concurring determination of the resident's decisional capacity was warranted. A clearly documented concurring physician's statement regarding the resident's decisional capacity when forgoing life-sustaining treatment (and in the presence of a qualifying condition as documented by the attending physician and another physician) would have resolved the scenario and set the course for the decision-making.

With regard to guardian involvement, the HRA notes that the guardian was directly involved in the situation. The HRA found evidence that the facility carried out many guardian directives for evaluations and referrals related to the cancer diagnosis and in a timely manner. And, the resident apparently agreed to those evaluations and referrals but refused any actual treatment options. However, the guardian and facility were at odds over the decisions related to the surgery, there was no indication that the facility attempted to resolve the disagreement and there was no reference to the situation in the resident's care plan.

Also of concern, the HRA found a history of the facility relying on the guardian's consent for other situations and in spite of the facility's statement that the resident could make independent decisions. The facility accepted the guardian's directives and consent when there was no conflict but when the resident objected, the facility favored the resident's position. This further points to the confusion and potential for harm that can result when decisional capacity statements are not consistent with Health Care Surrogate Act provisions and disputes are not addressed and documented in a resident's care plan. The HRA contends that the facility must acknowledge the guardian's role, follow care planning requirements and meet provisions of the Health Care Surrogate Act when such situations arise. **Therefore, the HRA substantiates rights violations related to a guardian's request for medical intervention, surrogate decision making and care planning and recommends the following:**

1. **Ensure compliance with the Nursing Home Care Act by addressing and**

documenting resident care needs, including conflicts, through the treatment planning process with input from the resident and guardian. Identify goals to address and resolve problems. If the facility disputes a guardian's request, address and document through the care plan process, including various means to address (e.g. transferring to another facility, court involvement, etc.).

2. **Ensure compliance with the Health Care Surrogate Act by documenting clear physician statements of decisional capacity when the facility believes a resident fully understands a procedure and repercussions, taking into account the facility's history of accepting a guardian's consent. When decisions involve the forgoing of life sustaining treatment, ensure that a concurring physician documents a statement of decisional capacity once it has been determined that a qualifying condition exists as documented by the attending physician and another qualified physician.**

3. **Develop policy related to life-sustaining treatment and advance directives as required in the Skilled and Intermediate Care Facilities Code.**

4. **Educate staff on the provisions of the Probate Act, the Health Care Surrogate Act and the new facility policy. Provide the HRA of evidence of this training.**

The HRA also offers the following **suggestion:**

- Regarding the facility's dispute over the resident's competence, we call attention to a section of the Probate Act which states that the guardianship can be modified or terminated with a restoration of capacity for the resident (755 ILCS 5/11a-19 & 20). The HRA **strongly suggests** that Sharon Healthcare consider these options when it questions the need for a guardian.

Complaint #2 - The facility did not follow a physician's orders regarding surgical preparation.

The HRA reviewed sections of the record that stated the resident was to be NPO (nothing by mouth) prior to the surgery. The HRA reviewed a physician's order from the facility physician, dated 6/12/12 which states the resident was to be NPO on 6/26/12 and a total laryngectomy was scheduled on 6/27/12. A nursing note, dated 6/25/12, states that the facility received the order for the resident to be NPO on 6/26/12. The nursing notes on 6/27/12 at 6:25am describe the soda incident involving the resident. The first mention of the incident in the notes reads "Cab here to transport resident to hospital. Resident approached while sitting in MDR writing letter. Resident had opened can of Coke in front of him. Resident states he isn't going to hospital to have surgery. This nurse asked resident if he knew he wasn't to have drank anything and resident said 'Yes.' Resident cont. to write letter at table. Approx. 1/3 can of Coke was gone. This nurse went to the front of building to inform cab driver of resident's decision." At 6:45am the nursing notes read "When arriving at front of building [guardian] was in lobby.

She asked if resident was going for surgery. She was informed of resident refusal. She was informed that resident was in MDR with opened can of Coke in front of him. She then stated she was going to call ERS to get resident to go. She was again told that resident refused to go to hospital. She then said that resident has cancer and needs the surgery. This nurse again stated that he refused and had an opened can of Coke in front of him. She then stated that this facility should have been able to keep him NPO." The notes state at 6:46am the "Resident was reapproached to go to cab. Resident again refused. This nurse said that [guardian] was there if he would like to talk to her and resident stated 'no.' Resident stated that he isn't going to have surgery."

In another nursing note on that same day, at 11:30am, it describes a meeting with the guardian and the facility over the phone. The nursing notes read that during the meeting "There were a couple of issues that were corrected by facility staff as follows 1) He was kept NPO all night, after getting up, dressed and directed to the cab to leave for surgery he flat out refused, he then went and bought a Coke and had only drank a small amount." This seems to contradict what was written earlier in the nursing notes. A Summary and Physician's Progress Note dated 6/27/12 states "Pt. refused surgery again. Drank [illegible word] Coca Cola in order to avoid surgery."

The Skilled Nursing and Intermediate Care Facilities Code reads "f) All medical treatment and procedures shall be administered as ordered by a physician. All new physician orders shall be reviewed by the facility's director of nursing or charge nurse designee within 24 hours after such orders have been issued to assure facility compliance with such orders" (77 Il Admin Code 300.3220). Section 300.1210 (d) (2) reiterates this requirement and states that "All treatments and procedures shall be administered as ordered by the physician. Section 300.1010 (f) states that "Physician treatment plans, orders and similar documentation shall have an original written signature of the physician. A stamp signature, with or without initials, is not sufficient."

The Nursing Home Care Act guarantees the resident's right to refuse treatment. (210 ILCS 45/2-104(c) of the Act)

Complaint #2 - Conclusion

A review of the allegation, the HRA discovered that there was a physician's order for the resident to be NPO for surgery. Documentation indicated that the resident obtained the soda on his own accord but also that the facility should have been able to keep him NPO through its supervision of the resident. At the same time, the HRA recognizes the resident's right to refuse, taking into account the provisions of the Probate Act and Health Care Surrogate Act when there is a court-appointed guardian**. Based on the complaint state and evidence, the HRA finds the complaint substantiated and provides the following recommendations:**

1. **Follow NPO orders as required under the Skilled Nursing and Intermediate Care Facilities Code by supervising residents who might access fluid or food. If a conflict is anticipated, address through the care planning process, including a plan should the resident refuse to comply with the NPO orders. Include the guardian and resident's input in the care plan.**

2. **When there is a court-appointed guardian, review all resident treatment refusals in terms of the provisions of the Nursing Home Care Act, Probate Act and Health Care Surrogate Act.**

3. **The HRA also suggests that the facility consider policy development/revisions to address NPO orders, resident refusals and the guardian's role.**

RESPONSE

Notice: The following page(s) contain the provider response. Due to technical requirements, some provider responses appear verbatim in retyped format.

LAW OFFICES OF
GARY A. WEINTRAUB, P.C.
465 CENTRAL AVE.
SUITE 100
NORTHFIELD, ILLINOIS 60093
(847) 441-8535
FAX (847) 441-0800

April 2, 2013

Certified Mail
#7011 3500 0003 0106 8564

Illinois Guardianship and Advocacy Commission
401 Main Street
Suite 620
Peoria, Illinois 61602

Re: Sharon Health Care Facilities
HRA Case No. 13-090-9003

Gentlemen and Ladies,

I represent the Sharon Health Care Facilities. On March 25, 2013, the Peoria Regional Office of the Human Rights Authority issued a "Report of Findings" in connection with the above matter. Enclosed is a "Response and Objections of Sharon Health Care Facilities" to such Report and the recommendations contained therein.

In the event that the HRA decides to make such Report or any of the findings or recommendation contained therein a part of the public record, the Facilities respectfully request that their Response and Objections also be made part of the public record.

Should anything further be required in connection with this matter, please so advise.

Thank you for your assistance.

Very truly yours,

Gary A. Weintraub

Gary A. Weintraub

GAW/g
encl.

PEORIA REGIONAL HUMAN RIGHTS AUTHORITY

HRA CASE # 13-090-9003

RESPONSE AND OBJECTIONS OF
SHARON HEALTH CARE FACILITIES

Sharon Health Care Elms, Inc.[1] [the "Facility"], a nursing home, respectfully disagrees with the HRA's conclusion that the Facility violated the "rights" of one of its resident by not forcing him to have a laryngectomy[2] -- which would have left him unable to speak for the remainder of his life -- which he refused. The resident was a 67-year old man who had advanced stage cancer of the larynx. He was ambulatory and able to bathe, dress, and feed himself. He went out every day to visit friends. He went out on community outings with staff, including shopping, where he would decide which items to purchase on his own.

The surgery was scheduled for June 27, 2012, but on that day he refused to go to the hospital or to have the surgery. [redacted] of [redacted] was present in the facility that morning (approximately 6:40 a.m.) and was immediately informed of the resident's refusal. The resident's attending physician, Dr. [redacted] (who had been his doctor for approximately the last 13 years), met with him later that morning [nurse's note, 6/27/12; 10:30 a.m.) and "... made a clear statement regarding the resident's understanding of the surgery and his prognosis without it" [Report, at 11]. He also indicated that "[e]thically and morally I cannot force resident to have this surg[ery]" [Report, at 6]. Upon being informed of the resident's refusal of surgery, the surgeon who had been scheduled to perform the surgery, Dr. [redacted] withdrew ("discharged the patient from his service" [Methodist consultation note, 7/18/12]). On July 16, 2012, the resident was admitted to Methodist Medical Center, where he was seen in consultation by the psychiatry service, the oncology service, the ENT service, and the Ethics Committee. Dr. [redacted] who saw the resident at Methodist, documented: "It was felt by myself and the psychiatry service that he fairly clearly did not want surgery. Hospice was recommended. This was also the recommendation of the ethics committee" [Discharge Summary – discharge date 7/24/12].

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[1] There are four facilities (Sharon Elms, Sharon Pines, Sharon Willows, and Sharon Woods) located in a complex in Peoria, which serve different resident populations/provide different levels of care. This matter relates only to one of the facilities, Sharon Elms.

[2] A laryngectomy involves the surgical removal of the larynx and the separation of the airway from the mouth, nose, and esophagus. Following the procedure, the patient breathes through an opening in the neck (called a "stoma").

Accordingly, the Facility disagrees with and objects to the Report of Findings issued in the above matter on or about March 25, 2013 ["Report"], and the conclusions reached therein.

Complaint #1: That the facility did not pursue a guardian's request for medical intervention in a timely manner.

Response: The HRA's conclusion is a based on a flawed and incorrect analysis. Although the HRA now asserts that its "... role is determine whether or not a resident's rights were violated by the facility with regard to facilitating the guardian's involvement" [Report, at 10], the guardian's "argu[ment] in favor of surgery for the resident in spite of the resident's voiced refusals" [Report, at 10-11] would itself have violated the most fundamental and inviolable rights of the resident.

The Illinois Supreme Court has made it clear that the right of personal inviolability, including the right to choose to have or to refuse medical treatment, is among the most fundamental rights of all human beings:

> ... we find a right to refuse life-sustaining medical treatment in our State's common law and in the provisions of the Illinois Probate Act.
>
> Under common law, *a patient normally must consent to medical treatment of any kind. Consent is required to maintain the right of personal inviolability*: "*No right is held more sacred*, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." (*Union Pacific Ry. Co. v. Botsford* (1891), 141 U.S. 250, 251, 11 S.Ct. 1000, 1001, 35 L.Ed. 734, 737.) Viewing this right in the context of medical treatment, Justice Cardozo stated, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages." (*Schloendorff v. Society of New York Hospital* (1914), 211 N.Y. 125, 129-30, 105 N.E. 92, 93.) This court has held that informed consent is a prerequisite to surgery. (*Pratt v. David* (1906), 224 Ill. 300, 79 N.E. 562.) Lacking consent, a physician cannot force medical care upon a patient, even in life-threatening situations. (*Cf. In Re Estate of Brooks*, 32 Ill.2d 361, 205 N.E.2d 435 (right to refuse life-saving treatment found in first amendment free exercise of religion clause).) Exceptions to the doctrine of informed consent do exist, for example, in emergency situations (6A C.J.S. *Assault & Battery* §7 (1975)) or when a minor needs care (*see, e.g.*, Ill.Rev.Stat.1987, ch. 111, pars. 4502, 4503.)

> Furthermore, because a physician must obtain consent from a patient prior to initiating medical treatment, it is logical that the patient has a common law right to withhold consent and thus refuse treatment. This right incorporates all types of medical treatment, including life-saving or life-sustaining procedures. Many of our sister States have based the right to refuse life-sustaining treatment wholly or partly on this common law basis. (*See, e.g., Conroy*, 98 N.J. 321, 486 A.2d 1209; *Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266; *Drabick*, 200 Cal.App.3d 185, 245 Cal.Rptr. 840; *Rasmussen*, 154 Ariz. 207, 741 P.2d 674; *Gardner*, 534 A.2d 947.) We find the reasoning of these opinions persuasive, and hold that in Illinois, the common law right to refuse medical treatment includes, under appropriate circumstances, artificial nutrition and hydration.
>
> *In Re Estate of Longeway*, 133 Ill. 2d 33, 549 N.E. 2d 292, 297, 139 Ill.Dec. 780, 785 (1989) (emphasis added)

And our Appellate Court has noted,

> Our supreme court has stated that "[l]acking consent, a physician cannot force medical care upon a patient, even in life-threatening situations." *Longeway*, 133 Ill.2d at 45, 139 Ill.Dec. 780, 549 N.E.2d at 297. *This same principle holds true for nonphysician health care professionals.*
>
> *Prairie v. University of Chicago Hospitals*, 298 Ill.App.3d 316, 698 N.E.2d 611, 619, 232 Ill.Dec. 520, 528 (1st Dist. 1998) (emphasis added)

As for nursing home residents, the Illinois Nursing Home Care Act also expressly provides that:

> Every resident shall be permitted to *refuse medical treatment* and to know the consequences of such action, unless such refusal would be harmful to the health and safety of others[3] and such harm is documented by a physician in the resident's clinical record. *The resident's refusal shall free the facility from the obligation to provide the treatment.*[4]
>
> 210 ILCS 45/2-104(c) (emphasis added)

---

[3] There is no suggestion in this case that the resident's refusal could possibly jeopardize the health or safety of others.

[4] The HRA recognizes this at one point in its Report [Report, at 10 ("... the Nursing Home Care Act recognizes the right of a nursing home resident to refuse treatment")], but, at another point, quotes the refusal of treatment provision of the Act selectively by omitting the last sentence ("[t]he resident's refusal shall free the facility from the obligation to provide the treatment") [Report, at 8].

[*See, also*, 77 Ill.Admin.Code 300.3220(i), to the same effect.]

Shortly after its decision in *Longeway*, the Illinois Supreme Court stated:

> ... the [Nursing Home Care] Act contains no provision forbidding a nursing home from acting in accordance with a court order. *A patient has the right to obtain or refuse medical treatment* (Ill.Rev.Stat.1987, ch. 111-1/2, par. 4152-104), *and not even the Department of Public Health is permitted to prescribe the course of treatment by a resident's personal physician* (Ill.Rev.Stat.1987, ch. 111-1/2, par. 4153-201). We do not believe that generalized references to providing food, water, and meals should override either a resident's specific right to refuse medical treatment, the definition of health or medical care found elsewhere in our law (*e.g.*, Ill.Rev.Stat.1987, ch. 11-1/2, pars. 804-10(a), (b)(1); *Longeway*, 133 Ill.2d at 41, 139 Ill.Dec. 780, 549 N.E.2d 292), or, for that matter (in any case to which they were pertinent), a resident's religious rights (Ill.Rev.Stat.1987, ch. 111-1/2, par. 4152-109).
>
> *In re Estate of Greenspan*, 137 Ill.2d 1, 558 N.E.2d 1194, 1204, 146 Ill.Dec. 860, 870 (1990) (emphasis added)

Decisional capacity.

In enacting the Health Care Surrogate Act [755 ILCS 40/1, *et seq.*] ["HCSA"], the Illinois General Assembly set forth the following finding:

> The legislature recognizes that *all persons have a fundamental right to make decisions relating to their own medical treatment*, including the right to forego life-sustaining treatment.
>
> 755 ILCS 40/5(a) (emphasis added)

The HCSA then provides (in Sec. 20(a)) that "[d]ecisions whether to forego life-sustaining or any other form of medical treatment involving an adult patient with decisional capacity may be made by that adult patient" [755 ILCS 40/20(a)]. Where a person is without decisional capacity (*e.g.*, irreversibly comatose or in a persistent vegetative state), such decisions may be made by a surrogate decision make (which includes a guardian) "... in consultation with the attending physician" [*see*, 755 ILCS 40/20(b)(1) and (b-5)(1)].

"Decisional capacity" is defined in the HCSA as "the ability to understand and appreciate the nature and consequences of a decision regarding medical treatment or foregoing life-

sustaining treatment and the ability to reach and communicate an informed decision in the matter as determined by the attending physician" [755 ILCS 40/10].

Adjudication as a disabled person does ***not*** mean that such person is without decisional capacity. Indeed, to the contrary, there remains a ***presumption*** that the person has decisional capacity:

> Under the HCSA, a person is *presumed to have decisional capacity* unless her attending physician states otherwise in writing and one other physician concurs.
>
> * * *
>
> ... the adjudication of Mrs. Austwick as a disabled person under the Probate Act, of itself, does not overcome the presumption under the HCSA that she has decisional capacity.
>
> *In re Estate of Austwick*, 275 Ill.App.3d 665, 656 N.E.2d 773, 776, 212 Ill.Dec. 176, 179 (1st Dist. 1995) (emphasis added) (holding Public Guardian did not have authority to consent to DNR order on behalf of disabled person who was able to make her own decisions regarding life-sustaining treatment)

See Am.Jur.2d Physicians, Surgeons, and Other Healers §160, at 272-73 (2002) ("A person's fundamental right to determine the scope of his own medical treatment and to refuse medical treatment is not lost if the patient becomes incompetent"; hence, "medical treatment may not be administered without adequately and judicially supervised protection"). Such judicial intervention is justified under the doctrine of *parens patriae*, in the state's capacity as the provider of protection for those who are unable to care for themselves. [Citation omitted.]

In re Estate of K.E.J., 382 Ill.App.3d 401, 887 N.E.2d 704, 716-17, 320 Ill.Dec. 560, 572-73 (1st Dist. 2008)

The HRA begins its analysis by noting that "[i]t is beyond the scope of the HRA to determine whether or not the resident in this case has decisional capacity in terms of Health Care Surrogate Act provisions ..." [Report, at 10]. This is the first flaw in the HRA's incorrect chain of reasoning. Decisional capacity is (a) presumed [*Estate of Austwick, supra*], and (b) was determined to exist by the attending physician in this case. [*See*, Report, at 11 ("... the physician made a clear statement regarding the resident's understanding of the surgery and his prognosis without it. The HRA commends the facility and the physician for pursuing and then documenting the resident's wishes and understanding of the surgery").]

The HRA then concludes that "... a concurring determination of the resident's decisional capacity was warranted" [Report, at 11]. Respectfully, the HRA has got it exactly backwards here. The resident is presumed to have decisional capacity. It is only a determination of the ***lack*** of decisional capacity (by the attending physician, to a reasonable degree of medical certainty) which is required to be documented in the resident's clinical record:

> ... A determination that an adult patient *lacks* decisional capacity shall be made by the attending physician to a reasonable degree of medical certainty. The determination shall be in writing in the patient's medical record and shall set forth the attending physician's opinions regarding the cause, nature, and duration of the patient's *lack of decisional capacity*. Before implementation of a decision by a surrogate decision maker to forego life-sustaining treatment, at least one other qualified physician must concur in the determination that an adult patient *lacks decisional capacity*.
>
> 20(c) of the HCSA [755 ILCS 40/20(c)] (emphasis added)

Austwick, supra (where the medical records contained "no physician's statement saying she lacked decisional capacity" [656 N.E.2d at 776; 212 Ill.Dec. at 179]) makes this clear:

> Under the HCSA, a person is presumed to have decisional capacity unless her attending physician states otherwise in writing and one other physician concurs. (... 755 ILCS 40/20(c) (West 1992).) There are no such statements in Mrs. Austick's medical records.
>
> 656 N.E.2d at 776; 212 Ill.Dec. at 179

There is no requirement for a second physician opinion where a resident has decisional capacity (which is presumed to be the case). Furthermore, the requirement for a concurring physician statement only applies in circumstances where a surrogate decision-maker seeks to forego life-sustaining treatment, not to force treatment. Nothing in the HCSA supports forced treatment or surgery on an adult person with decisional capacity.

In consultation with the attending physician.

Assuming, *arguendo*, there had been a determination here that the resident lacked decisional capacity made by his attending physician and another physician had concurred (neither of which occurred here), then the decision of the surrogate decision-maker (here, the guardian) would have had to have been made "in consultation with the attending physician" [755 ILCS 40/20(b)(1) and (b-5)(1)]. But the attending physician did not support forced surgery over the resident's objection.

Substituted decision-making standard.

Again, assuming, *arguendo*, that (i) the resident was without decisional capacity, (ii) this had been determined by his attending physician, (iii) this had been concurred in by a second physician, and (iv) the guardian had been called upon to make a decision "in consultation with the attending physician" (none of which occurred here), then, under the HCSA,

> Decisions whether to forego life-sustaining treatment on behalf of ... an adult who lacks decisional capacity may be made by a surrogate decision maker or makers in consultation with the attending physician, in the order or priority provided in Section 25. A surrogate decision maker shall make decisions for the adult patient *conforming as closely as possible to what the patient would have done or intended under the circumstances*, taking into account evidence that includes, but is not limited to, the patient's personal, philosophical, religious and moral beliefs and ethical values relative to the purpose of life, sickness, medical procedures, suffering, and death. Where possible, the surrogate shall determine how the patient would have weighed the benefits and burdens of initiating or continuing life-sustaining treatment against the burdens and benefits of that treatment.
>
> 755 ILCS 40/20(b)(1) (emphasis added)

> The doctrine of substituted judgment requires clear and convincing proof of the incompetent person's intent before a court may authorize a surrogate to substitute his or her judgment for that of the incompetent. Any lesser standard would "undermin[e] the foundation of self-determination and inviolability of the person upon which the right to refuse medical treatment stands." (*Longeway*, 133 Ill.2d at 49, 139 Ill.Dec. 780, 549 N.E.2d 292.)
>
> *Curran v. Bosze*, 141 Ill.2d 473, 566 N.E.2d 1319, 1326, 153 Ill.Dec. 213, 220 (1990

The surrogate decision-maker is required to look first to any actual, specific expressions of intent by the resident regarding the type of medical treatment. [*Longeway*, 549 N.E.2d at 299-300; 139 Ill.Dec. at 787-88.]

> Ascertainment of what the patient would decide must be based on clear and convincing evidence of the patient's intent, derived either from a patient's explicit expressions of intent or from knowledge of the patient's personal value system. *Longeway*, 133 Ill.2d at 49-51, 139 Ill.Dec. 780, 549 N.E.2d 292, citing *In re Jobes* (1987), 108 N.J. 394, 415, 529 A.2d 434, 445.

* * *

> ... [the patient's] imputed choice cannot be governed by a determination of best interests by the public guardian, AUL, or anyone else. Otherwise, the substituted-judgment procedure would be vitiated by a best-interests guardianship standard, elevating other parties' assessments of the meaning and value of life – or, at least, their assessments of what a reasonable individual would choose – over the affected individual's own common law right to refuse medical treatment.
>
> *In re Estate of Greenspan*, 137 Ill.2d 1, 558 N.E.2d 1194, 1202, 146 Ill.Dec. 860, 868 (1990)

This is not a case where the person has never previously expressed his views about the circumstances facing him. Here, the resident expressed what his wishes and intent were. Under these circumstances, allowing a third-party to impose a substituted judgment would violate, rather than exercise, his right to self-determination and control of his own body. The guardian cannot ignore the clear expressions of intent or elevate its own assessment of what someone else might chose over the resident's actual, explicit expressions of his intent.

It is hard to avoid mentioning the irony in this case. On the one hand, the State agency, [redacted] (or at least one arm of it, HRA) criticizes the facility for not forcing a resident to have a surgery which he refused. On the other hand, the [redacted] did not disagree with the resident's decision enough to petition the Probate Court (which had appointed it as guardian in the first place) for authority to compel the resident to have the surgery.

Physician-Patient Relationship.

In Illinois, the relationship between a person who happens to reside in a nursing home and his or her physician is directly between patient and physician. [*See*, §2-104(a) of the Nursing Home Care Act (210 ILCS 45/2-104(a) ("A resident shall be permitted to retain the services of his own personal physician at his own expense or under an individual or group plan of health insurance, or under any public or private assistance program providing such coverage"); 77 Ill.Admin.Code 300.3220(a) (same).]

> It is well established that, at common law, a patient's consent is required before a physician may administer any medical treatment to that patient. *In re Estate of Longeway*, 133 Ill.2s 33, 44, 139 Ill.Dec. 780, 549 N.E.2d 292 (1989). A corollary to the consent requirement is that a patient has the right to refuse medical treatment, even if the patient's life is in jeopardy. *Longeway*, 133 Ill.2d at 45, 139 Ill.Dec. 780, 549 N.E.2d 292. Also well established is that a common-law battery is the

> unauthorized touching of the person of another. *Gaskin v. Goldwasser*, 166 Ill.App.3d 996, 1011-12, 117 Ill.Dec. 734, 520 N.E.2d 1085 ([4th Dist.] 1988). At the crossroads of these well-established principles exists the tort of medical battery .... In a medical battery case, an injured party can recover by establishing either that there was no consent to the medical treatment performed, that the treatment was against the injured party's will, or that the treatment substantially varied from the consent granted. *Hernandez v. Schittek*, 305 Ill.App.3d 925, 930, 238 Ill.Dec. 957, 713 N.E.2d 203 ([5th Dist.] 1999). Under such circumstances, a battery has occurred because the person administering the medical care intentionally touched the person of another without authorization. *Goldwasser,* 166 Ill.App.3d at 1012, 117 Ill.Dec. 734, 520 N.E.2d 1085.
>
> *In re Estate of Allen*, 365 Ill.App.3d 378, 848 N.E.2d 202, 210-11, 302 Ill.Dec. 202, 210-11 (2nd Dist. 2006)

If the State is going to be about dragging a conscious, ambulatory person away and cutting out his voicebox against his will, it will be without the participation of health care providers. Not this facility. Not the attending physician (who "... disagreed with the decision [of the guardian to force the surgery) on an ethical level because the resident did not want the treatment" [Report, at 1]; "[e]thically and morally I cannot force resident to have this surg" [Report, at 6]). Not a second physician who saw the resident while he was in the hospital ([redacted]). Not the Ethics Committee at [redacted] Not the surgeon who had been scheduled to perform the procedure. [Report, at 2.] And most likely not any other licensed physician in this State.

In situations where (i) a resident is not irreversibly comatose or in a persistent vegetative state, and (ii) the resident's attending physician does not determine that he lacks decisional capacity, and (iii) the resident refuses to consent to surgery, and (iv) the guardian seeks to substitute its own judgment and to compel the surgery notwithstanding the resident's refusal, the guardian has a procedure available – to petition the probate court (which appointed it) to force the person to submit to surgery.[5]

---

[5] This is the procedure followed in *Austwick*, although in that case it was the resident (through the Legal Advocacy Service of the Illinois Guardianship and Advocacy Commission) who petitioned the probate court to terminate and remove a DNR order which the Public Guardian had consented to on her behalf. The probate court found that the Public Guardian had no authority to consent to a DNR for an adult who was not determined by her attending physician to lack decisional capacity and ordered the DNR removed. The Appellate Court affirmed. [*In re Estate of Austwick*, 275 Ill.App.3d 665, 656 N.E.2d 773, 212 Ill.Dec. 176 (1st Dist. 1995).]

Complaint #2: That the facility did not follow a physician's order regarding surgical preparation.

Response: The HRA's conclusion is factually incorrect.

The physician's order (of Dr. [redacted] who was scheduled to perform the surgery) was for NPO (nothing by mouth) on the evening of June 26, 2012 (after midnight), in contemplation for surgery scheduled for the following morning, June 27 (which the resident subsequently refused). The resident was, in fact, kept NPO all night – no food or fluids were provided by the facility. The following morning, after the resident awoke and dressed himself, and after he had refused to go for surgery, he went to one of the vending machines in the facility and purchased a Coke for himself. Restraining him from doing this would have violated his rights. What, if anything, the HRA thinks the facility should have done to prevent him from doing this is not elucidated.

The facility followed the physician's order. No further policy development or revision is called for or appropriate.

Conclusion.

Accordingly, the Facilities object to the proposed findings. In the event that such findings are included in any publicly released report, the Facilities respectfully request that these comments and objections also be included in such public report.

Thank you for your consideration.

Sharon Health Care Facilities

LAW OFFICES OF
GARY A. WEINTRAUB, P.C.
465 CENTRAL AVE.
SUITE 100
NORTHFIELD, ILLINOIS 60093
(847) 441-8535
FAX (847) 441-0800

May 28, 2013

Certified Mail
#7011 3500 0003 0106 8601

Mr. Gene Seaman
Illinois Guardianship and Advocacy Commission
401 Main Street
Suite 620
Peoria, Illinois 61602

Re: Sharon Health Care Facilities
HRA Case No. 13-090-9003

Gentlemen and Ladies,

I represent the Sharon Health Care Facilities. In response to the letter of May 22, 2013, of Meri Tucker, Chairperson, Peoria Regional Human Rights Authority, the Facilities respectfully submit the enclosed "Supplemental Response and Objections of Sharon Health Care Facilities."

In the event that the HRA decides to make its Report or any of the findings or recommendation contained therein a part of the public record, the Facilities respectfully request that their prior Response and Objections and this Supplemental Response and Objections also be made part of the public record.

Should anything further be required in connection with this matter, please so advise.

Thank you for your assistance.

Very truly yours,

Gary A. Weintraub

Gary A. Weintraub

GAW/g
encl.

PEORIA REGIONAL HUMAN RIGHTS AUTHORITY

HRA CASE # 13-090-9003

SUPPLEMENTAL RESPONSE AND OBJECTIONS OF
SHARON HEALTH CARE FACILITIES

Respectfully, Sharon Health Care Elms, Inc. [the "Facility"] disagrees with the HRA's position and analysis in this matter (which involves one resident's choice to forego a medical procedure he did not want). Although the incorrectness of the HRA's Report was pointed out at length in the Facility's prior response, the HRA is now entirely silent as to this, but nevertheless makes recommendations, none of which has anything to do with the circumstances or situation involved here. [This matter does not involve (a) care planning, or (b) advance directives, or (c) a person who was comatose or in a persistent vegetative state.] Accordingly, the Facility disagrees with the recommendations communicated by letter dated May 22, 2013 (apparently following consideration by the HRA at its meeting of May 15, 2013) and submits this Supplemental Response in response and objection to such recommendations:

> Recommendation #1 – Nursing Home Care Act; guardian's disagreement with resident's medical decision/care plan applicability. The Facility complies with all applicable provisions of the Nursing Home Care Act. The Facility welcomes, and encourages, the participation of a guardian in care plan conferences. However, as discussed more fully in the Facility's prior response, the input of a guardian has limits,[1] and a resident's right of personal inviolability requires that his or her right to choose to have or refuse medical treatment be honored, unless such refusal would be harmful to the health and safety of others [§2-104(c) of the Nursing Home Care Act; 210 ILCS 45/2-104(c); 77 Ill.Admin.Code 300.3220(i)]. With respect to the HRA's suggestion that, "if the facility disputes a guardian's request" that the resident undergo a particular medical treatment, the facility should address and document this through the care plan process by "e.g. transferring to another facility, court involvement, etc.":
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> 1. It is not the Facility, but rather the resident, who is disputing.

[1] For example, under Section 11a-14.1 of the Probate Act [755 ILCS 5/11a-14.1], no guardian of a disabled person (except a duly appointed Public Guardian or OSG) has the power to place his ward in a residential facility unless so authorized by court order. This statutory provision further specifies that, with respect to residential placement, the guardian (including a Public Guardian or OSG) "... shall make decisions in conformity with the preferences of the ward unless the guardian is reasonably certain that the decisions will result in substantial harm to the ward or to the ward's estate" [*ibid.*]. And, under the same statute, it is the duty of the guardian to "... pursue appropriate alternatives [with respect to residential placement] as needed" [*ibid.*].

2. A nursing home cannot unilaterally transfer a resident to another facility. Unless the resident agrees to move, the procedures set forth in the Nursing Home Care Act [210 ILCS 45/3-401, *et seq.*] and the Illinois Department of Public Health's implementing regulations [77 Ill.Admin.Code 300.3300] must be followed. The proposed discharge action must be documented by giving a notice of involuntary discharge and opportunity for a hearing before the Department. This is not a care planning issue. As to "court involvement," it is for the guardian, if he/she disagrees the resident's decision to have or forego a particular medical treatment and believes that the presumption of decisional capacity [*In re Estate of Austwick*, 275 Ill.App.3d 665, 656 N.E.2d 773, 776, 212 Ill.Dec. 176, 179 (1st Dist. 1995)] should be overcome, to petition the Probate Court (which appointed it as guardian in the first place) to overrule the resident's decision.

Recommendation #2 -- Health Care Surrogate Act/decisional capacity. Again, as the Facility previously pointed out [Facility Response, at 4-5], the HRA has got it exactly backwards here. The resident is presumed to have decisional capacity. It is only a determination of the ***lack*** of decisional capacity (by the attending physician, to a reasonable degree of medical certainty) which is required to be documented in the resident's clinical record:

> ... A determination that an adult patient *lacks* decisional capacity shall be made by the attending physician to a reasonable degree of medical certainty. The determination shall be in writing in the patient's medical record and shall set forth the attending physician's opinions regarding the cause, nature, and duration of the patient's *lack of decisional capacity*. Before implementation of a decision by a surrogate decision maker to forego life-sustaining treatment, at least one other qualified physician must concur in the determination that an adult patient *lacks decisional capacity*.
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> §20(c) of the HCSA [755 ILCS 40/20(c)] (emphasis added)

Austwick, supra (where the medical records contained "no physician's statement saying she lacked decisional capacity" [656 N.E.2d at 776; 212 Ill.Dec. at 179]) makes this clear:

> Under the HCSA, a person is presumed to have decisional capacity unless her attending physician states otherwise in writing and one other physician concurs. (... 755 ILCS 40/20(c) (West 1992).) There are no such statements in Mrs. Austick's medical records.
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> 656 N.E.2d at 776; 212 Ill.Dec. at 179

Recommendation #3 – Skilled and Intermediate Facilities Code -- advance directives. The Facility complies with the Skilled and Intermediate Facilities Code. The Facility implements residents rights under living wills and powers of attorney for health care in accordance with the Living Will Act [735 ILCS 35 (which addresses a person's wishes regarding death-delaying procedures where death is imminent and the person is no longer able to give directions regarding the use of such death-delaying procedures)] and the Powers of Attorney for Health Care Law [735 ILCS 45].[2] The Facility requests copies of any such advance directives as part of its admission procedures. This, however, has nothing to do with this matter. The resident in question had no advance directive.

Recommendation #4 – "Educate staff … on Probate Act, Health Care Surrogate Act, and new facility policy." N/A.

Recommendation #5 – Follow NPO orders. The Facility follows all NPO orders. The Facility followed the order in this case. [*See*, Facility Response, at 10.]

Recommendation #6 – Where there is a guardian, review all resident treatment refusals in terms of Nursing Home Care Act, Probate Act, and Health Care Surrogate Act. Resident refusals of major medical treatments are rare. When they do occur, the Facility notifies the guardian and requests that the guardian participate in discussions with the resident regarding the potential benefits and risks of the recommended procedure.

Recommendation #7 – Further policy revisions. The Facility has all policies required of it in terms of honoring a resident's fundamental right to make decisions regarding his or her medical treatment. This is a legal/statutory – not a policy – issue. The Nursing Home Care Act expressly provides that:

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[2] In enacting the Powers of Attorney for Health Care Law [755 ILCS 45/4-1, et seq.], the Illinois General Assembly reiterated:

> The General Assembly recognizes the right of the individual to control all aspects of his or her personal care and medical treatment, including the right to decline treatment or to direct that it be withdrawn, even if death ensues. *The right of the individual to decide about personal care overrides the obligation of the physician and other health care providers to render care or to preserve life or health.*
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> 755 ILCS 45/4-1 (emphasis added)

> Every resident shall be permitted to *refuse medical treatment* and to know the consequences of such action, unless such refusal would be harmful to the health and safety of others and such harm is documented by a physician in the resident's clinical record. *The resident's refusal shall free the facility from the obligation to provide the treatment.*
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> 210 ILCS 45/2-104(c) (emphasis added)

IDPH similarly so provides in its regulations [77 Ill.Admin.Code 300.3220(i), to the same effect] The HRA recognizes this in its Report, at 10 ("... the Nursing Home Care Act recognizes the right of a nursing home resident to refuse treatment").

Conclusion.

Accordingly, the Facility objects to the proposed recommendations. In the event that either the prior Report or the current recommendations are included in any publicly released report, the Facility respectfully requests that these comments and objections also be included in such public report.

Thank you for your consideration.

Sharon Health Care Facilities