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REPORT OF FINDINGS ADVOCATE CHRIST MEDICAL CENTER– 21-040-9003 HUMAN RIGHTS AUTHORITY- South Suburban Region

INTRODUCTION

The South Suburban Regional Human Rights Authority (HRA), the investigative division of the Illinois Guardianship & Advocacy Commission has completed its investigation into an allegation concerning Advocate Christ Medical Center. The complaint stated that a recipient was not allowed communication with persons of choice. If substantiated, this allegation would violate the Illinois Administrative Code for Hospitals and Ambulatory Care Facilities (77 Ill. Admin. Code Part 250), the Code of Federal Regulations (28 C.F.R. 36.201), the Illinois Probate Act (755 ILCS 5/11a-17 and 5/11a-23) and other federal regulations.

Located in Oak Lawn, this 788-bed acute care hospital provides specialty care services including cancer, cardiovascular, heart and kidney transplantation, brain and spine, and women's health. This hospital is part of the Advocate Health Care Network and the Aurora Health Care Network.

METHODOLOGY

To pursue the investigation, the hospital's administration and medical staff were interviewed. The complaint was discussed with the adult recipient's parent, who is his legal guardian, and his records were reviewed with written consent. Relevant hospital policies were reviewed. Additionally, the HRA reviewed documentation of the hospital's response to his parental guardian's requests for visitation and other information that were not part of the record.

COMPLAINT SUMMARY

The complaint stated that the recipient was not allowed visitation with persons of choice. It was reported that the recipient's parental guardian/emotional support person was informed that due to concerns about the covid-19 pandemic that visitation would no longer be allowed beginning on the fourth admission day. It was reported that the recipient's physical medical condition had started to decline on or around the tenth

admission day and that limited visitation was allowed before his death. It was reported that the recipient's parental guardian had begged to be allowed to provide emotional support at his bedside and that he had died without any family members at his bedside.

FINDINGS

Information from the record, interviews and program policy

The Advocate Christ Medical Center record indicated that the recipient was a direct admission to the hospital's Neurological Critical Care Unit (NCCU) on March 13th, 2020. He was transferred from a local hospital's emergency department after seeking medical care for flu-like symptoms and a Computed Tomography Scan had showed multiple brain lesions with edema. He had a grand-mal seizure that had lasted for several minutes and a tracheal tube was inserted into his body to help him breathe prior to his transfer to the receiving hospital's NCCU. The hospital's admission record documented that the recipient's mother is his legal guardian. She told the hospital that the recipient was developmentally disabled at birth and communicates usually with single words and lives in a group home. She told the HRA that a copy of the guardianship order was provided on the admission day. For March 14th, 2020, a Physical and History Report documented that the recipient was "critically ill" and would require a high complexity of decision-making and active titration of therapies to preserve his life. This reportedly was explained including his clinical condition and plan of care to his parental guardian and stepfather at his bedside. His record contained signed medical consents for a brain biopsy and general anesthesia for the procedure.

For March 15th, 2020, a physician's note documented sepsis brain abscesses, suspicion of streptococcus infection, and bacteremia. The recipient's parental guardian's and stepfather's questions reportedly were answered by the physician at his bedside. His parental guardian told the HRA that she was informed that lesions of similar appearance had been found on his liver, kidneys, and lungs. She reported that he had tried to open his eyes and believes that he had tried to move his hand and foot upon commands. She said that a staff person came in his room to remove the ventilator and overheard them talking to him about trips they had previously taken and started asking them questions about their travels. Then, they were questioned by a nurse about the corona virus even though they told her that they had not done any traveling during the past five years. She said that she was informed that due to the covid-19 virus that visitation was not allowed when she had presented to the hospital on the 16th. A nurse on the medical floor told her the same thing. Later that same day, a physician told her that she could not visit him on the medical unit and that she could not provide emotional support for him and that he would not even know if she was in his room.

The recipient's parental guardian told the HRA that there were many reasons why she needed to be with him during his hospitalization. For example, she said that she had told the hospital's admission staff that the recipient was called by his middle name. However, she said that his name preference was not shared with the staff on the medical floor because they were constantly calling him by his first name. She said that he needed stimulation and emotional support to help him to get better and was responding to her and

his stepfather when visitation was allowed. She said that the hospital's Speech Therapist told her that applesauce and apple juice were offered during the swallowing assessment without success. However, she had told them that he would never swallow food items or beverages made from apples. She reportedly was informed that the swallowing assessment would be attempted again and that she would be called if needed.

For March 17th, 2020, a physician's note documented the recipient that had multiple "enhancing" brain lesions and awakens to pain and does not sustain eye opening and was able to intermittently follow commands. The recipient's parental guardian told the HRA that she had phone communication with him during the visitation restriction and he said "yes" about four times on the 18th and "goodbye" on that next day. She said that a nurse had called her because he was upset, and he said "yes and bye" to her on the 20th. And, the nurse told her that he was calmer after she had talked to him. Later, the hospital's Risk Manager told her that she would call her on the 21st and let her know if she could visit him. She reported that the hospital's Risk Manager told her on that next day that visitation would not be allowed and suggested that she should ask the nursing staff about communication by phone or FaceTime. She reported phone communication with him on that same evening.

For March 22nd, 2020, the recipient's parental guardian told the HRA that she was informed that he had more lesions on his brain and bigger in size. She said that the hospital's Risk Manager told her that she would call her back because she had begged her to do something about the visitation restriction. The Charge Nurse told her that she could come to the hospital and sign the papers for his transfer to the hospice unit when his physical health fails. She reported that his physical health "took a turn for the worse" around the 23rd and that the hospital's Risk Manager told her that visitation would be allowed on that same day. She reportedly was screened for covid-19 upon her arrival to the hospital. The progress notes documented that the recipient's parental guardian was at his bedside on the 23rd and said that she was "grateful" because this was the first day that she was allowed visitation. She told the Advance Practitioner of Nursing and the Social Worker of Palliative Care that she was hoping to be allowed daily visits because she believed that he would benefit if someone familiar was with him. She was informed that he had multiple brain abscesses and was positive for streptococcus intermedius and due to the "swiss cheese" effect on his brain that his neurological condition would not likely get any better. She said that she was hopeful that he would not need a feeding tube after antibiotic medication therapy and wanted to get a second opinion from a Physician of Infectiousness Diseases. She was trying to find a long term acute care facility to meet his needs and was hopeful for his recovery. She gave permission for the hospital's chaplain to visit him. She had asked about putting a camera in his room so she could communicate with him outside of the hospital and was informed that she needed to talk to the charge nurse about this issue. The recipient's parental guardian told the HRA that he was responsive to her on the 23rd and that she had stayed with him until she was asked to leave the hospital at 8:00 p.m.

For March 24th, 2020, the progress notes documented that the recipient was more lethargic and that the Advance Practitioner of Nursing and the Social Worker of

Palliative Care and parental guardian were at his bedside. His parent said that she had talked to the Physician of Infectious Diseases and was not sure if she wanted to continue with his present treatment plan. The Advance Practitioner of Nursing told her that due to his medical condition that he was at risk for complications including, but not limited to infection, aspiration, and decubitus ulcers. His parent said that she had talked to the unit social worker about placement at a named long term acute nursing facility near her home. However, she was unable to visit the nursing facility due to the covid-19 restriction on visitation. She was encouraged to consider hospice care when medical interventions were no longer effective or result in a meaningful recovery. She reportedly acknowledged that she understood that the recipient would never function at his previous baseline but was hopeful he would be able to interact with her. She told the staff that antibiotic medication should be continued and to give him some time for recovery. She said that he had enjoyed receiving a phone call from his biological father, stepfather, and cousins on that previous day. She asked if communication could be setup with his housemates and was informed that this might be stressful for them. A nursing note indicated that the recipient was intubated because his breathing was labored on that same day and that the Physician of Pulmonary Care and parental guardian were at his bedside when the hospital's Rapid Response Team (RRT) was called. His parental guardian told the HRA that she and his stepfather were allowed visitation after the intubation procedure was done.

For March 25th, 2020, the progress notes documented that the recipient's parental guardian, the Advance Practitioner of Nursing, and the Social Worker of Palliative Care had talked about the process involved in the withdrawal of life support interventions that included medical equipment, food, breathing tube, and pain medication. And, she was informed that he would stay on the Intensive Care Unit for 24 hours and then he would be taken to a private room, and two people would be allowed visitation and no physicians would be called. According to the progress notes, the recipient's parental guardian said that she understood that his physical medical condition might not improve, and she would consider "comfort-focused care." She reportedly became emotional describing how he had been responding to her before the RRT intervention and was hopeful that he would improve. She said that she did not want him to suffer or to be uncomfortable as his physical medical health declined. She was informed that his symptoms would be addressed as needed. She said that she was hoping that she would be allowed to visit because she did not want him to be alone. His parental guardian told the HRA that she had begged to be with him during the phone calls about discontinuing life support interventions.

For March 26th, 2020, the progress notes documented that the recipient's parental guardian told the Social Worker of Palliative Care that she had concerns about visitation and plans after his death. She was informed that visitation might become more restrictive over time. Later, she told the physician that she wanted to be at the recipient's bedside and that it was difficult to make decisions about his care. She said that she did not want him to be reintubated if he was extubated. And, she was not sure about managing his care if he was discharged from the hospital under hospice care. The recipient's parental guardian told the HRA that she told the Social Worker of Palliative Care and the

Advance Practitioner of Nursing that she had made some arrangements for his likely death when the discontinuation of life support interventions was discussed. She said that she was informed by the Advance Practitioner of Nursing that the hospital's rules on visitation now restricted people over the age of 60 years and only one person would be allowed visitation with the patient for one hour.

The Advance Practitioner of Nursing told the HRA that the recipient's mother was usually at his bedside when she had assessed his clinical condition. She said that her role was to support his mother in developing care goals for him. She reported that she does not remember talking to his mother about any specific age requirement for visitation because the hospital did not have such a policy. She said that visitation was restricted for all patients at the beginning of the corona virus pandemic and timeframe in question. The hospital's Director of Civil Rights told the HRA that the hospital was "hit hard" during the early stages of the covid-19 pandemic and that the hospital was trying to ensure the safety of patients and to prevent the spread of the virus. She said that the recipient did not live with his parental guardian and that she was not his constant companion. She said that his parental guardian was offered remoted communication with him. Additionally, the Manager of the NCCU reported that the staff were focused on helping family members with downloading video communication applications such as Zoom because they realized that some of them lacked technical skills concerning this issue.

For March 27th, 2020, the recipient's parental guardian told the HRA that the physician told her that the recipient's heart rate dropped to "30" several times on that previous night and that this had happened again while he was making rounds on that morning. He told her that she would be allowed visitation with him. She had called the Social Worker of Palliative Care and told her that she was on her way to the hospital. She had asked her to go to the recipient's bedside because she did not want him to be alone. His stepfather reportedly was not allowed visitation when they arrived at the hospital. She said that the physician shook his head "no" when she had asked if he was going to "make it." She reportedly was provided with educational information about the withdrawal of life support interventions and acknowledged an understanding that this would result in his death. She said that the social worker and the hospital's chaplain were present in the recipient's room when she gave consent for the withdrawal of life support interventions. The social worker had stayed with her and the staff started removing his feeding tube and the monitoring machines. She said that she was asked to leave the hospital around 5:45 p.m. and a nurse told her that she probably would not be allowed visitation again. She reported that she had asked a physician to please help her to be able to visit with him again as she was leaving the medical floor. The Manager of the Surgical Intensive Care Unit told the investigation team that a nurse told her that the recipient's parental guardian was at his bedside for about five to six hours on the 27th.

For March 28th, 2020, the recipient's parental guardian told the HRA that she was informed that the recipient's vitals had dropped to 89/45 and that he was feverish, and that visitation would be allowed. His stepfather was also informed that he would be allowed visitation. She said that they were informed that he had died upon their arrival to the medical floor about one hour later. And, they had stayed in the room with him until

around 8:00 a.m. A progress note indicated that the preliminary cause of death was acute respiratory failure due to sepsis. For March 29th, 2020, the recipient's parental guardian said a staff person from the hospital's network support department had returned her call a week later concerning the visitation restriction issue. For March 29th, 2020, the recipient's parental guardian told the investigation team that she had received a return phone call a week later from hospital's network out-of-state advocacy support department concerning the visitation restriction issue. She said that the hospital's staff person did not know that the recipient had died, and she was informed that someone would contact her because wanted to get a copy his medical record. The recipient's parental guardian told the HRA that she had signed a release of information form for a copy of his medical record. However, she has not received this at the time the complaint was filed with the HRA.

The hospital's "Patient Rights & Responsibilities" policy dated on December 12th, 2019 stated that patients have the right to visits with persons of choice. According to the policy, visitation may be restricted for the well-being or safety of the patient or others or if medically contraindicated in the patient's care. It lists some specific reasons for limiting or restricting visitation such as a pandemic or infectious disease outbreak.

The hospital's Covid-19 policy on visitation updated on March 15th, 2020 stated that the hospital is implementing a "no" visitor policy as a proactive measure to keep patients and team members safe and to reduce the potential for contracting and spreading the virus. All visitors who meet the exclusion criteria must pass a health screening. The exclusions criteria include:

- 1) Pediatric caregivers (2)
- 2) Caregivers necessary for the emotional well-being of the patient (1)
- 3) Partner and midwife/doula of a laboring mother (2)
- 4) End of life situations (number of visitors will be determined on a case-by case basis)
- 5) Emergency department companion (1)
- 6) Outpatient area companion (1)
- 7) In-person discharge instructions (1)
- 8) Professionals assigned to assist with procedures (1)

According to the hospital's policy, a centralized screening area would be designated for individuals who meet the visitation exception criteria list. The hospital's staff were asked to help patients to connect with their loved ones by other communication means such as phone calls and FaceTime. The hospital's Covid-19 policy on visitation updated on March 17th, 2020 does not include caregivers necessary for emotional support as exclusions in the policy but the criteria concerning end of life situations was not removed.

The hospital's staff told the HRA that there was confusion about visitation because a glitch in the computer system had removed the emotional support criteria exception in the updated policy on the 17th. The staff said many times that the recipient's

parental guardian was offered communication via remoted means with the patient during his hospitalization.

CONCLUSION

The Illinois 77 Administrative Code Section 250.250 states that,

(a) Each hospital shall establish, in the interest of the patient, policies regarding visitation on the various services and departments of the hospital. It is recommended that visitors be limited to two per patient at any one time.

b) In times of increased incidence of communicable disease in the community, the hospital should consult with the local health officer regarding further restriction of visitors.

Section 504 of the Rehabilitation of Persons with Disabilities Act defines a recipient of services as having a physical disability that substantially limits one or more major life activities.

The Americans with Disabilities Act states that persons with disabilities are entitled to reasonable accommodations.

The Code of Federal Regulations Section 36.201(a) states that,

No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation.

The Illinois Probate Act Section 5/11a-17 states that the personal guardian shall make provision for the ward's support, care, comfort, health, education, and maintenance.

Section 5/11a-23 states that,

Every health care provider and other person (reliant) has the right to rely on any decision or direction made by the guardian ... to the same extent and with the same effect as though the decision or direction had been made or given by the ward.

The complaint stated that a recipient was not allowed communication with persons of choice. The record documented that the recipient was admitted to the hospital's NCCU for multiple brain lesions with edema on March 13th. He was developmentally disabled, lived in a group home and his communication skills were very

limited. His parental guardian told the HRA that due to the covid-19 pandemic that visitation was restricted on the 16th. She reported that a physician told her that she could not provide emotional support for him and that he would not even know if she was in his room. The hospital's policy started restricting visitors on March 15th, 2020 policy but included caregivers necessary for the emotional well-being of the patient and end-of-life visitors for patients (the number of visitors will be determined on a case-by case basis) in the policy criteria exclusions list. The HRA understands that the hospital may place reasonable restrictions on visitation because of the covid-19 pandemic to prevent the spread of the virus to patients and staff such as limiting the numbers of visitors at any one time, limiting visitors to those who able to meet the patient's needs, screening visitors for possible illness, etc. However, the recipient's parental guardian believes that she falls under the caregiver necessary for the emotional well-being of the patient as well as his home staff. The caregiver or support person criteria exclusion was removed from the hospital's visitation restriction policy due to a glitch in the computer system on March 17th, 2020, per the staff interviewed.

The record and parental guardian indicated that limited visitation was allowed on the 23rd, 24th and the 27th because his physical medical health had started to decline. His record contained documentation that his parental guardian was involved in updates with his treatment team and during the visitation restriction that she had some communication by remote means with him. His parental guardian told the HRA that she had desperately tried to gain access to her son to provide emotional support at his bedside. She reported that she did not believe that appropriate accommodations such as relaxing the visitation restriction were made to meet the recipient's needs and that she had contacted the hospital's Risk Manager, the hospital's out-of-state advocacy support department, and community agencies/individuals concerning this issue. However, she said that she did not get the help needed and that he died without any family at his bedside on the 28th. This case is not only about communication with persons of choice, but it highlights support and consideration concerning end-of-life issues. The Authority substantiates the complaint stating that a recipient was not allowed communication with persons of choice such as his parental guardian/emotional support person on March 16th thru the 22nd, 25th and the 26th of 2020.

RECOMMENDATION

1. The hospital is reminded that recipients with disabilities have the right to a support person of choice with them while hospitalized if needed. The hospital's visitation restriction policy dated on March 15th, 2020 included caregivers as a criteria exclusion in the policy. However, the hospital's policy was not followed by the staff when the recipient's parental guardian was not allowed visitation with him on the 16th and other days mentioned in the report.

SUGGESTIONS

1. The hospital should provide the necessary services to ensure effective communication with individuals who have disabilities and limited communication skills.

2. Develop strategies on how to communicate with individuals who have disabilities and require hospitalization.

3. Ensure records are provided to the guardian as requested and allowed under HIPAA

RESPONSE

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



750 W. Virginia Street
Milwaukee, WI 53204

April 15, 2021

To Whom It May Concern:

Advocate Aurora Health (AAH) appreciates the opportunity to respond to the investigation and findings regarding this matter. Please accept our response to the findings identified in your report dated March 15, 2021 (Case#21-040-9003).

As part of its findings IGAC recommended that patients with disabilities be permitted a support person of choice while hospitalized if needed. Although not required by law, it is our practice to permit an emotional support person for patients with disabilities. It is documented that the Guardian visited the patient at bedside on: 3/13/2020, 3/14/2020, 3/15/2020, 3/17/2020, 3/18/2020, 3/22/2020, 3/23/2020, 3/24/2020, 3/25/2020, 3/26/2020, and 3/27/2020.

It was suggested that AAH:

1. Ensure effective communication with individuals who have disabilities and limited communication skills.
 - a. AAH has a Language Services Department that ensures patients are apprised of their rights to effective communication and necessary communication assistance is in place. In addition, we have a comprehensive policy and protocols to ensure all individuals with limited English proficiency and special communication needs have access and full enjoyment to all AAH programs and services.
2. Develop strategies on how to communicate with individuals who have disabilities.
 - a. In addition to our aforementioned policy, when appropriate, and necessary a consult from Speech Pathology would be obtained to identify the unique communication needs of a patient.
3. Ensure records are provided as requested.
 - a. AAH policy is aligned with HIPAA's 30-day requirement to fulfill records requests. The medical records request submitted by the Guardian was fulfilled 5 days after the submission and within the required timeframe.

Points of clarification to the final report:

- This incident happened during the beginning of the COVID-19 global pandemic. Advocate Christ Hospital was the IL epicenter of this pandemic and, among the top 10 ECMO (Extracorporeal Membrane Oxygenation) centers for COVID globally. In accordance with the local health officer recommendations, CDC guidance, and in alignment with other health systems, AAH had to quickly establish a visitation protocol rooted in the best health interest of our patients and staff.
- The Director of Quality did not make reference to a “glitch in the computer system.” We believe this interpretation references the rapidly changing visitation protocol during the initial weeks of the pandemic.



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Milwaukee, WI 53204

- AAH never had a 60+ year old age limitation on approved visitors.
- The report cites the following State and Federal Regulations: IL 77 Administrative Code Section 250.250, Section 504 of the Rehabilitation Act, Americans with Disabilities Act, Code of Federal Regulations Section 36.201(a), IL Probate Act Section 5/11a-23. None of the regulations cited require a companion be permitted for “emotional support.” AAH does recognize the need for individuals with disabilities to be allowed a companion to assist with functions or tasks related to care and activities of daily living. Our visitation policy reflects an allowance for reasonable accommodations related to disability needs.

We are disappointed the Guardian felt she did not get the help she needed and sympathetic to what she has been through. We sincerely respect the vital role guardians play in care and decision making. The Guardian participated in frequent communication with the clinical team and was not excluded from any decision making. When the Guardian requested an accommodation to be at bedside, leadership granted her request. Reasonable accommodations were made to allow in-person visitation and other virtual communication options.

Sincerely,

Joelle Espinosa
Director of Civil Rights