December 12, 2023 Evelien Wiersma 6443 River View Line Chatham, Ontario N7M 5T1 519-359-1458

Chatham Kent Health Alliance 80 Grand Ave. West Chatham, Ontario N7L 1B7

Attention: Dr. Nagib Khalifa

CC: CEO: Lori Marshall

Hospital Manager: Matt VP of Operations: Caen Suni

VP of Transformation: Meredith Whitehead

Director of ED/ICU: Natalie Clark

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Dr. Kristin McCulloch

Patient Relations Specialist: Taryn McGregor-Van Hooren

Jon Nesbit: The Canadian Independent

College of Physicians and Surgeons of Ontario

College of Physicians and Surgeons of Ontario:

Our dearly loved husband, father, grandfather and great grandfather, Clare Wiersma, was brought to the CKHA by ambulance the evening of December 23, 2021. He had tested positive for covid on December 19 using a rapid home test.

We called our doctor on December 21 since Clare seemed to be getting worse, suffering from a high fever and dropping oxygen levels. The advice given was to continue to monitor his fever and oxygen levels and if his oxygen dropped to 85-87 to call an ambulance. Strange advice from a doctor but we trusted she knew what she was doing. So on Dec. 23 when his fever spiked and his oxygen levels dropped to 85 and he basically collapsed, we entrusted him to what we thought and believed to be a group of people who would care for him and fight for his life. Instead, this was the beginning of a nightmare for our family that lasted just 7 days until he died the morning of December 30 2023.

I would like to address three areas:

- 1. Our experience with CKHA during Clare's brief stay there
- 2. Our experience at CKHA on the day he died.
- 3. The medical care and treatment or lack thereof during Clare's stay

Our experience with CKHA from December 23-December 30 2021:

I want to express our thankfulness to all the nurses that cared for Clare during his brief stay there. One stands out in particular. Her name was Hannah, who worked on the medical floor. She not only cared for him medically but took time to ask us questions about his job, his likes and dislikes, his family so she could better care for him and communicate with him. Thank you Hannah for going above and beyond!

We were very disturbed by the way the hospital staff isolated Clare from his family right from the start. It is common knowledge that a patient does much better when surrounded by a supportive and loving family. The family knows the person well and would be able to advise the staff when and if certain behaviours or responses were out of the norm. We would have been able to comfort Clare and advocate for him. For example, on Clare's first day at CKHA he seemed confused and his answers were flat. We would have quickly realized that he was probably not hearing well since he depended on his hearing aids to hear.

We realize there were certain measures in place to limit the spread of Covid but our oldest daughter had natural immunity since she had Covid in October. Each day she would offer to stay with her Dad 24/7, not leave the room or hospital just to be there to encourage and care for her father. She was refused each time. This has left its mark on her for life.

There was a definite lack of communication. We called several times each day to see how Clare was doing. The only people we were able to talk to was either a clerk or a nurse. We had questions and concerns they could not answer. Each time we were told we had to talk to a doctor, yet no doctor ever contacted us though we requested that each day. The only time we talked to a doctor was on Dec. 25 and he only talked about intubating Clare. He did not take the time to listen to our concerns and basically hung up on us when we asked him about using different medications to fight for Clare's life.

We would have appreciated receiving Clare's charts and reports each day so we could see what was being done and have advocated for him.

To isolate a patient from his or her family increases the possibility of a poor outcome for the patient. Every person needs someone beside them to encourage them, to help them, to love and comfort them and to advocate for them when they are ill. To leave someone completely alone, isolated from the people they love is at best ill advised, and at worst cruel and inhumane. I, as Clare's wife, and our children live with the trauma and deep pain of not being allowed to be with Clare/Dad when he most needed us, to this very day.

Our family's experience at CKHA on December 30 2021, the day Clare died

This day started with an early morning phone call to our oldest daughter informing her that her Dad was not doing well and was not expected to live. Imagine her shock when she was told that the family could not come and be with her father even when he was at the point of death. She informed the person she was talking to that we were coming anyway since no one was going to keep us from being there when Clare needed us.

After arriving at CKHA it took us quite some time to convince the staff and in particular the manager Matt, that the family should be with Clare at this time. He finally agreed to "allow" two people to go to

be with Clare. The rest of the family had to stay behind even though two family members were fully vaccinated.

I and our oldest daughter Joeline were selected to go be with Clare.

Since we had not seen Clare in person since December 23 it was quite a shock to see him with all kinds of tubes and machines around him. To see him so helpless and to know that the end was near was devastating. I tend to react to stressful situations like that by becoming very lightheaded and dizzy. That is what happened this time. The staff provided me with a chair but the lightheadedness didn't quickly disappear. Code Blue was called and I was taken from my husband's side to ER. Once there some tests were run but it was obvious that nothing major was going on. I requested to return to be with Clare but was denied.

In the meantime, our youngest daughter who had just had a baby twenty days prior, arrived at the hospital hoping to see her dad one last time, only to be rudely told to leave by security guards on duty. They would not even allow her to be in the breeze way. She was told to get a covid test done before being allowed into the hospital. This lack of compassion is quite shocking. The security guards could have explained what she needed to do in a kind and caring way, taking into account they were dealing with someone whose father is dying. We were all puzzled by this since neither I nor our oldest daughter was required to take a test prior to going to Clare's room. The inconsistencies are glaring and make one wonder about the rules in place.

In the end this one question resounds: Is this any way to treat a family whose dearly loved husband and father lay on his death bed? Keep in mind that all of this took place in front of her fully vaccinated brother and sister.

None of our other children were allowed to wait in the lobby of the hospital for hopefully their turn to see Dad. Instead they were told to wait outside. The lack of compassion and care for our family is incomprehensible.

Since I was not allowed to be with my husband the manager "gave permission" to our fully vaccinated second oldest daughter to join her sister to be with her dad. Our kids realized that I needed someone to be with me and asked the manager to let one of them go to the ER. Initially, that was refused as well. Then, as" a special favour", the manager said that one of our kids could go to be with me with the stipulation that if they then would go see their Dad they would not be allowed to return to the ER to be with me. What an incredibly difficult choice for our kids! Two of them live out west and had not seen their dad since he became ill. Our son, who lives our west, made that difficult choice to be with me and never saw his dad alive. No one should be forced to make such choices.

In the meantime, both our son and I and the girls up in ICU kept asking the manager and staff to let me return to be with my Clare. Each time we met with refusal and were told it was AMA. As if that mattered to us! I can still see the manager standing in the doorway, with a smile on his face, refusing to let me go. After many requests which were steadfastly refused, out of the blue, a nurse came and told our son he could take me up to the ICU department. We were puzzled, anxious and afraid but so relieved to finally be able to go back to be with Clare. When the elevator doors opened, giving us a direct view of Clare's room, we both realized that Clare had already died and that we were too late to say our final good byes. The pain of that is with me each day. I cannot fathom how those who are to care for the patient and his/her family could deal so cruelly and insensitively with us at such a time as this.

Even after Clare died, we were not allowed to be with him together as a family. Only two at a time we were told. I have no words to describe this added pain. In addition, the staff in the ICU showed little to no compassion. Their desk was right outside of Clare's room and they were carrying on laughing and talking while we were trying to process our loss. I realize that they deal with illness and death on a regular basis but should they not show respect and compassion for a grieving family? When asked if I could have some water they refused even that.

To this day I cannot understand the lack of care and compassion we experienced on December 30 2021. It's etched in my mind and the minds of our children and grandchildren and continues to cause great stress and trauma to an already very difficult loss.

Concerns about the medical treatment of Clare:

When we called for an ambulance we fully expected that Clare would be thoroughly checked over and if necessary receive appropriate treatment for his illness. We also expected that since we were not allowed to be with him, that we would receive at least daily updates and would be able to speak with the doctor(s) who were looking after him. We had full confidence that the doctors and nurses looking after our Clare would do everything they knew to fight for his life. That was not our actual experience.

I want you to be aware that we had a nurse with ER and ICU experience initially go over Clare's health records. She red flagged a number of things which led us to turn for more help elsewhere. This resulted in a Police Investigative Team and four doctors going over Clare's records. The doctors looked at the records independent of each other. Everyone had deep concerns about the procedures used, the medications used and the lack of care that was glaringly evident at times. They were also very concerned with the lack of communication between the family and the team looking after Clare. In addition, they questioned the decision to intubate Clare since both he and I (his wife) had clearly indicated we did not want that to happen.

Please allow me to list the concerns we as a family have in point form:

- 1. We were denied access to Clare from the time he was admitted to his death. It is a well-documented fact that patients have a better chance at survival and recovery when surrounded by loving family members who can look after the patient, who know him well and can encourage and comfort him, keep an eye on the medication and procedures suggested and advocate for him when needed. We feel that by keeping the family away the staff could do whatever they wanted without our approval, input or knowledge. Clare had no advocate, no one to keep an eye on his treatment, no one to comfort and support him. This is horrific and continues to cause trauma in our lives to this day.
- 2. Lack of treatment with antibiotics or other medications when Clare was admitted. He received oxygen and Tylenol but no antibiotics for his pneumonia.
- 3. Clare had no comorbidities. His blood sugar levels were normal. He did have arthritis but did not take any medication for that other than an occasional Advil. For that reason we question the use of an arthritis medication that has the known side effect of the lungs presenting as pneumonia which would also interfere even more with his condition. Clare would not have agreed to take that.
- 4. We question whether he was properly hydrated during his stay especially the last 2-3 days of his life.

- 5. We note that Dexamethasone was started on Dec. 25. We believe this should have been started on his admittance since he had been ill for several days already.
- 6. When sepsis set in no treatment was given to combat that. This is especially concerning since Clare's death certificate indicates that septic shock is one of the causes of his death.
- 7. Acidosis also set in and again no treatment was given.
- 8. A CXR test should have been done on a daily basis but the health records do not indicate that.
- 9. Throughout his stay Clare repeatedly told us that he was not being looked after properly. The most glaring incident of that was shortly before he was intubated. The staff had asked him that morning if he would agree to be proned. He said yes but asked if they could help him use the bathroom prior to that. He texted us to call him. When we connected with him it had been over two hours and no one had come to help him to the bathroom. This is gross negligence and lack of care especially considering he was in the ICU.
- 10. Throughout Clare's stay we would request certain treatments or medications be given but were always informed that the person we were speaking to had no authority to change his treatment and that we would have to ask the doctor. Yet we were never given access to a doctor. This is especially concerning since we were not able to be with Clare to monitor what was being done. The only time we talked to a doctor was a call to advise us that this doctor felt that Clare should be on a ventilator. When he asked Clare regarding intubation, Clare said no. We told the doctor that Clare and I had agreed not to be ventilated based on the research we had done. The doctor did not tell us of any risks nor indicate the low percentage of survival for patients that have been ventilated. We told him not to ventilate Clare and to call us if things became critical. That did not happen. Instead we received a call informing us that Clare had been ventilated. We did not find a consent form for Clare's intubation. We find it very disturbing that a patient undergoes surgery against the wishes of the patient and his family.
- 11. While going through Clare's Medical Administration Records, many questions arose regarding the medication given, the dosage and how often they were given. Especially the last few days of his life. Many of the medications used would have interfered with breathing and heart function. For some there is an indication to not use them together yet that was done. So many questions that had we been there could have been asked and explained and perhaps resulted in a change that would have given Clare a better chance at fighting this disease. The one that stands out the most is the use of Midazolam, an end of life drug in combination with phentanyl. I realize that these two are sometimes combined when surgery is performed but in Clare's case they would have further interfered with his breathing and would have severely interfered with his chance to fight off and recover from his illness.
- 12. According to Clare's Health Records he received one dose of antibiotics about three hours before his death. We are quite curious as to the timing and use of an antibiotic at that point in time. We feel he should have been given antibiotics well before then. First, for his pneumonia and secondly for the sepsis that set in.

It has been almost two years and yet the trauma of being kept from the person I love most on earth and knowing that he was not treated according to his and my wishes continues to haunt me. It is my desire that the hospital will take a serious look at the procedures they have in place. I would like some clear and precise answers from you specifically addressing the 12 concerns stated above and those expressed in the latter part of this letter. I am hoping that the executive branch and the staff will do some soul searching to see how they can make changes to prevent situations like ours from occurring over and over. I also believe your personnel need some training in how to come alongside families in the midst of tragedy. Our experience was horrific and I don't want any other families to have to go through a similar experience.

Let me end with some quotes from your own documents and my response to those:

Patient Rights and Responsibilities:

As a patient, you have the right to:

• Be treated with respect, dignity and independence

The way each day's report started showed a definite lack of respect, in fact, I would propose to say that it showed prejudice/ Clare's experience in the ICU also lacked in the respect and dignity factors

• Effective communication, information and education

We certainly did not have effective communication – Clare would ask us what his prognosis was and said that he was not being told anything. We did not receive much information even when we requested it.

Be fully informed about your treatment options

Neither Clare nor I were fully informed about treatment options. We were given one option, intubation. When we questioned Dr. Ali about that he became irate and basically hung up on us. Nor did he fully explain the negative aspects of intubation and the extremely low survival rate.

Make an informed choice and give informed consent to your treatment.

It's difficult to give informed consent when we received little to no information regarding treatment. Clare and I had studied the use of ventilators and had concluded that we did not want to have that treatment. I know that Clare said no to the intubation option as did I. When talking to Dr. Ali we asked him not to intubate until he had talked to us once more. That did not happen. I question whether there was consent given. I can find no record of that in the health records we obtained.

As a patient you are responsible for:

Actively participating/partnering in your care

Clare complained on several occasions that he was not being informed of his condition or of the treatment given or planned for the future. He was very frustrated by that.

Communicating with your health team

It was only with our help that the health team finally realized after Clare had been there over 36 hours that he was having difficulty communicating since he could not hear them without his hearing aids. Even when that was resolved the health team did not clearly communicate with him or us. We tried by calling 2-3 times a day but often did not get to speak to even a nurse and never to a doctor until Dr. Ali called re intubation.

Patient Role and Safety:

- The patient is encouraged to be an active member of your healthcare team. It goes on to say "this means taking part and being involved in every decision about your care.
 Again, Clare and we were in the dark as to his prognosis and care. His and our questions were not answered.
- Quote: "You may be asked to sign a consent form for certain tests, procedures and treatments. Before signing, make sure you know and understand the benefits and risks. You have the right to refuse treatment.

As I mentioned earlier we did not find a consent form for the intubation nor were we fully informed as to the risks involved in that procedure. As far as I know Clare refused intubation as did I.

Lastly, let me quote from your mission statement:

At the Chatham-Kent Health Alliance our Mission is:

Together, Growing a Healthier Community

The "together" includes everyone: CKHA staff, physicians, community partners and especially CKHA's patients and their care partners. We know that to truly live our mission, we must collaborate with our patients and their families and learn from the knowledge that comes from their lived experiences.

My gut response to this is "Really?" This most certainly was not our experience. Clare was isolated from us and we from him. We did not receive the information we needed to advocate for him. We were largely kept in the dark as to the medication given, his symptoms, and his prognosis. Every day we were told his oxygen levels and temperature but not much else. Had we been able to be there with him we could have kept an eye on his medication and care. We did not experience the working/collaborating that is mentioned here. Something went terribly wrong in the care or lack thereof that Clare was given. I believe that had this collaboration taken place, Clare might still be with us today.

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