FROM THE INSIDE

A Letter to Denise

Matthieu Le Dorze^{1,2}, Nancy Kentish-Barnes^{2,3}, Sadek Beloucif^{2,4} and Elie Azoulay^{2,3*}

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Dear Denise,

You will not read this letter.

This letter is written as a tribute to you, to express our gratitude for the effect you have had in strengthening the foundational principles that underlie the way we practice medicine. You have often been in our thoughts since that evening in March 2020 when you came to the emergency room short of breath and showing all the other signs of Covid-19. Your condition was such that within a short period of time you have been unable to breathe on your own. A bed was free in our ICU, where you could have received artificial ventilation. But you were not admitted. The reason for this was not your years living with cancer that was now nearly cured, nor your heart failure, or your advanced age. It was your decision. You knew beds were scarce due to the surge in the pandemic, and you did not want to take the last bed. You wanted it to be available for a patient with the age of your children or grandchildren. Your need for oxygen was so great that you wanted to be sure there would be enough oxygen for everybody. And there was enough.

For a long moment, we worried that we might have influenced your decision by our answers to your questions. And yet it is true that when oxygen alone is no longer sufficient, artificial ventilators in the ICU are the only way to maintain breathing while the infected lungs heal when they do heal. In the best of cases, the technical, noisy, and at times aggressive environment in the ICU leaves protracted physical and psychological aftereffects in patients who are able to overcome the lung infection,

as well as in their family and friends. Unfortunately, many patients do not survive this ordeal, and the grieving families are left with deep emotional wounds that may heal only with great difficulty [1, 2].

I remember first meeting you, the expression in your eyes, your dignified reserve when I examined you while the emergency physician fixed her worried gaze on your oxygen saturation numbers. You did not complain: your suffering was silent. We tried to understand how simple means might improve your situation. With the emergency physician, the nurse, and the nursing assistant who were caring for you that evening, we sat down for a moment. Together, we tried to parse through your situation based on the objective information available to us. We wanted to take the best decision, with you, with your son, for you, and we felt how vitally important it was to respect your wishes. We agreed that you had been quite vulnerable before the infection and that your current condition was serious. We became certain that admission to the ICU would be unable to have you back to your life trajectory. ICU admission would without doubt carry a risk of obstinately striving to avoid the unavoidable, at the cost of potential suffering for you and your relatives [3]. And so we decided that there was no need to challenge your wishes, as we would have if they seemed inappropriate. Your decision to leave the last ICU bed to another, and your perception that the machines would stubbornly persist in their actions only to prolong your suffering and not the length or quality of your life, prevailed. We did not try to change your mind, because we agreed with you. Talking to your son was precious. We shared—you, your family, and your team—the same care project. And most importantly, the decision was made with you, regardless your COVID status, as we would have taken the same decision whatever the cause of your respiratory failure.

We remember, Denise, that after you had settled into your room on a conventional ward with your loved ones, we came to visit you twice and also to speak with your son and your grandchildren. We also tried to reassure the

*Correspondence: elie.azoulay@aphp.fr

² University of Paris, Paris, France

Full author information is available at the end of the article

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nurses whose eyes asked us silently whether we couldn't "try something" in the ICU. In other situations, we might have reevaluated your condition daily to determine whether changes had occurred that made ICU admission an option. Instead, we reminded your team of the need to respect your wishes, of the decision-making path that we had followed, and of your refusal to move toward unreasonable therapeutic obstinacy. We worked with our colleagues in the ward to provide you with the care that would make you as comfortable as possible during this difficult phase. We will never forget that you asked us to go and take care of the patients who had a chance of recovery. You were a few days away from the end of your life but your smile was endless. We arranged to allow your family to be present. You died in peace. We will never forget the serenity and gentleness of your large black eyes.

When I returned to the ICU, I experienced a strange feeling when I saw the empty bed that could have been for you. It was available because a patient had been transferred 800 km away, to a region spared by the pandemic. This empty room received a patient less than one hour later. He did not have Covid-19 but meningitis with seizures for which he needed immediate lifesaving interventions. Know this, Dear Denise: because of this extraordinary pandemic, we must sometimes choose which patient will have the last bed, the last ventilator, while another patient will not receive these resources. This is not an empirical choice, these are never easy decisions, and we are fully aware of their impact on patients, families, and staff. Providing non-beneficial care or care that is not at odds with patient's values is a source of moral distress. This perception of inappropriate care leads to intra-team conflicts and is a source of faster nurse's turnover [4]. We are aware that it is often easier to do and escalate life-sustaining therapy rather than to meticulously weight potential benefits from every decision. How can this morally and emotionally difficult tension be resolved? By carefully identifying the patient most likely to benefit from ICU admission, in terms of length or quality of life. This is entirely different from a random choice made, for instance, by drawing lots or accepting the first patient who arrives, thus depriving others arriving later but less severely ill of a chance of survival.

Dear Denise, we are grateful to you for this extraordinary medical, human, and social experience. We will think of you whenever a difficult medical decision will have to be taken. We will remember your words and the

imperative necessity to reach out to each patient to evaluate the situation in all its singular details. We will recall the moment spent discussing your condition with our emergency room colleagues and the imperative necessity of sharing opinions before making a decision. We will remember what we saw in the eyes of your son when he understood the inevitable outcome and the imperative necessity of allowing the family a role in decision-making and in accompanying their loved one. We will remember the empty room that you could have occupied, and the need to realize that priority given to an individual can be superseded by the priority given to the community, on condition that the fundamental principles and values of healthcare are understood, protected and respected.

When patients in our ICU reach the end of their lives, we always encourage their family members to take the time to say goodbye to their loved one. Families who have not been able to say goodbye look back with regret on their experience several weeks or months later and find the grieving process even more difficult [2]. It is our turn now, Dear Denise, to say goodbye.

Author details

¹ Département d'anesthésie Réanimation, Lariboisière Hospital, APHP, Paris, France. ² University of Paris, Paris, France. ³ Médecine Intensive et Réanimation, FAMIREA Study Group, APHP, Hôpital Saint-Louis, Paris University, 1 avenue Claude Vellefaux, 75010 Paris, France. ⁴ Département d'anesthésie Réanimation, Avicenne Hospital, APHP, Bobigny, Paris, France.

Compliance with ethical standards

Conflict of interest

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