# The costs of caring

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### **Essay/Personal Reflection**

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On October 3, 2022, *Cost of Living* debuted on Broadway, delivering to audiences a sobering yet humorous exploration of disability, caregiving, power, poverty, and disjointed relationships in our modern moment (Phillips 2022). The play, written by Martyna Majok, won the Pulitzer Prize for Drama in 2018 after premiering in the Williamstown Theatre Festival. For clinicians – or for anyone involved in the act of palliative caregiving – its continued value far exceeds the price of admission.

Cost of Living features a four-person cast split into two pairs, whose scenes alternate by means of a turntable stage that allows their parallel worlds, located in modern-day New Jersey, to remain separate until the final scene. One pairing features John (Gregg Mozgala), a wealthy young man with cerebral palsy studying for his PhD at Princeton, and Jess (Kara Young), who recently graduated from Princeton College and is seeking employment as a health aide, partly to survive and partly to finance her mother's health care. The other pair comprised Eddie (David Zayas), a 50-something truck driver, and Ani (Katy Sullivan), who is quadriplegic and has undergone bilateral leg amputations following a recent car accident. Eddie and Ani are married but have separated since the accident; their scenes take place in Ani's new and "criminally beige" apartment in Bayonne (Majok 2018).

Following a long prologue delivered by Eddie, from a bar in Brooklyn, the younger pair opens the play in John's apartment. John is funny, charming, fully aware of his physical limitations while never inviting pity. Mozgala's convincing performance (the actor himself has cerebral palsy) challenges any simplistic reading of John as the innocent victim of circumstance. Despite his severe disability, he is the one with the money, and his heavy gaze and self-assured smile betray a keen awareness of his social status (Soloski et al. 2022). Nor is Jess the archetypal underdog. She does lack money, stable employment, local support, and a place to live, and these barriers cause genuine suffering for her and her family, but her physical strength and mobility provide access to worlds unreachable by her employer, however equal the two may be in intelligence. As Jess admits: "No, I'm not not-privileged either."

I spoke with the cast of *Cost of Living* after one Broadway performance, and Kara Young emphasized to me the surprising power of her character's position. This is a young woman with nobody to rely on, completely uncertain about herself, and into her life comes a wealthy and successful person who *needs her*. Young encouraged me to think about what this sense of need might do to the psychology of a caregiver. As I reflected on their most intimate caregiving scenes – Jess shaving John, undressing him, lifting him from his chair and into a seated shower – I saw less the straightforward power dynamic of employer and employee and more a complex layering of physical and social advantage. Jess may be caring for John, but she is also using him, and in any such relationship, there is danger that insufficient time will be given to prevent the pain that comes from misused leverage.

This is exactly what does happen in their final scene together, when Jess, who has developed romantic feelings for John, arrives at his apartment on a Friday evening, thinking she has been asked on a date. She has canceled her usual shift at the bar – for her, financial vulnerability is worth the chance for genuine affection – but, shortly after her arrival, John tells Jess that *he* is going on a date. Giddy and ostensibly naïve, he asks for a shave and shower before meeting with Madelyn, from "*actual* Oxford." A reckoning follows. Jess confronts John and presses him to admit to his manipulation, and John appears, for the first time, almost shameful, but nothing is reconciled. John offers overtime pay and moves into the bathroom, and then, after a brief moment of indecision, Jess leaves the apartment.

Eddie and Ani follow a very different journey. Abandonment and distrust already haunt their relationship and explain much of Eddie's effort to provide for his estranged wife. Their scenes are less physically demanding than those of Jess and John, but their emotional hurdles are imposing. Unlike Jess, Eddie is no professional caregiver and has no prestigious education. Unlike John, Ani lacks financial and social means and is new to her disability. These mutual disadvantages burden Eddie as he tries to atone for his implied desertion of Ani following her accident.

Yet their deficits also make room for a solidarity never achieved by the other, more endowed partnership. The younger characters have a longer future ahead and a

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shorter history but they are always tired, always pressed for time. Jess moves sleeplessly between multiple jobs while John stays up late into the night writing academic papers. Eddie and Ani have nowhere to go and nobody else. They have only time, and Eddie's valor in this play comes through his astounding persistence, his willingness to endure silence and insult, to take the time needed to care for another person.

Ani, for her part, offers more insult than silence, and understandably so, but this is precisely where Eddie shows his virtue as a caregiver. His history is one of relational and moral failure, and his guilt is no purer a motive for caregiving than Jess' insecurity, but he demonstrates remarkable patience, humility, and self-forgetfulness. He dances to lighten the mood when Ani is sad, then stops when he realizes that his dancing hurts her. He arrives to the apartment searching for things to do, no matter how menial or unglamorous.

There comes a moment when he is bathing Ani, sitting on a stool beside her porcelain bathtub while she lies motionless in a pool of bubbles. A piano concerto plays on the radio. Eddie tells Ani that he always wanted to learn the piano but never did; then he raises her arm onto the edge of the bathtub and fingers a playful, yet precise rendition of the song on the radio. The slow intimacy of this gesture is inextricable from the time it takes, from the time Eddie has invested in caring for Ani, from the time Ani has spent rebuilding her trust for Eddie.

Definite happiness, however, is beyond imagination for the characters of *Cost of Living*. By the final scene, Ani has died of a pulmonary embolism and a chance encounter has led to a meeting between the two caregivers. Eddie offers Jess – who has been sleeping in her car throughout the winter – rewarmed pizza and a room in his apartment. The night is freezing but Jess stands in the doorway. She apologizes, citing life itself as the grounds for her distrust: "It's just unfortunate," she says, "that some people have already lived a lot of life before they meet other people." She leaves

the apartment, but not before saying, almost bashfully: "Thanks fer ... trying." The play ends on a more hopeful note, but Jess' penultimate line could form the epigraph to the entire production. In the same way that Ani trusts Eddie for his humility and patience, Jess is grateful for his effort and concern. She knows that these things take time, that they require vulnerability, and so are costly treasures.

Besides its humor, emotional force, and intimate performance, Cost of Living affords palliative care professionals a priceless gift: a vision of caregiving in tune with time. The play, which does not mention palliative care specifically but could well be a theatrical demonstration of its importance, shows what that time and that care might be worth in our modern medical context. Whether this means the extra call to a bereaved family member, or the institutional decision to provide more space for conversation between clinicians and their patients, the provision and use of time remains a fundamentally humanistic endeavor in this most human of professions. Time may be money but it is also the medium in which we live, in which our stories of health and illness unfold, and the most valuable resource we can give to our patients. Because medical care - and palliative care especially - is about neither time nor money. As Gregg Mozgala told me of theater (which is, after all, the mirror held up to life): "it's about stories."

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