

ethics advisory boards. Dhanda argues that bioethicists should apply their critical reflective skills to technology development within the corporate environment.

In view of significant debate in the bioethics literature about the risk of bioethics becoming a rubber stamp or public relations tool, Dhanda's arguments are bound to stir up controversy. Yet, as he quite convincingly argues, it is only through maintaining their objectivity and transparency that bioethicists can effectively help industry. The utility of bioethicists for industry lies not in improving public relations, but in highlighting those areas where there is or is not consensus in order to help industry determine what research to conduct and how to ethically develop new technologies. With the intense focus of the popular press on the actions of biotechnology companies, tame bioethicists will be recognized as such and will only hurt a company's image and shareholder value. The details of how bioethicists are to work objectively and with integrity with the biotechnology industry remains to be worked out, but I agree with Dhanda that such participation is essential. *Guiding Icarus* is a must read for those interested in understanding how bioethics can help industry develop ethically and socially responsible biotechnologies.

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### Room for a view

## For the love of Alex

Vera's dreams were shattered when she awoke to find her husband cyanotic in bed next to her. They had immigrated to Canada years ago to build a new life. Both had worked long and hard, raising their daughters, improving their home, saving for a comfortable retirement, the reward they would enjoy later, together.

justing Alex. As we talk, she readily reveals her heart. I learn that Alex worked in a factory for almost 30 years, Vera in a store. I hear the horrible story of heartburn that was not heartburn and about Vera's frantic attempt at CPR. I hear that she wants her husband alive. I hear, beyond the words, the regret for things taken for granted.



Fred Sebastian

But later is this: a palliative care bed in a chronic care ward. The notes on Alex's chart are dismal: "chronic vegetative state," "anoxic brain injury," "sad case of a 62-year-old man." The emergency response team restarted his heart, but cerebral anoxia has taken his person away. He is comatose, his arms and legs drawn into rigid flexion. His eyes are vacant, his mouth a tense grimace. Beside his bed a box hums, connected to a PEG tube. Increased rigidity in response to pain is Alex's only reaction to the world.

I introduce myself to Vera. I tell her, presumptuously, that I will be Alex's doctor and that my goal is to work with her to keep Alex comfortable. Vera is tall and slender, with large strong hands that are always hovering over and ad-

Vera wants Alex alive — not just comfortable. What does "alive" mean for Alex? What does it mean for Vera, for me, for the nurses? With some dismay, I let the nurses know that I cannot write a DNR order.

In time, the calls from the nurses start — not about Alex, but about Vera. Vera is always at his side, constantly interfering with nursing tasks and protocols, always wanting things done differently. Vera will not have Alex left alone. When she is at work, her elder daughter must stay with him. Vera only leaves at night when Alex is "settled," long after visiting hours have ended.

Visits to Alex are difficult. Pinned to a bulletin board are photos of a tall, handsome man with an accordion, the life of the party. The proud father of

the bride. The beaming grandfather at a baptism. He is one half of a lifetime love affair. Now, lying in his hospital bed or perched awkwardly in a gerichair, he is an absence guarded by pictures of the Blessed Mother.

From Vera I hear a litany of complaints; from the nurses, equal and opposite laments. Vera washes Alex, turns him, does physiotherapy, massages him, feeds him and gives him his medication. Nobody can do for Alex what Vera can do for Alex. Some nurses sympathize with her; others are like sparks to dynamite. Vera has become a patient: she is stressed, working half-time at the store and spending obsessively long hours caring for her husband. She assures me that I don't have to be her doctor; she already has one, whom she will see if necessary. There are case conferences with social workers, priests, chaplains, the palliative care team, the hospital risk management staff. Vera states that it is Alex who is suffering and that we should be occupied with *him*.

Inevitably, Alex suffers complications: aspiration pneumonia, urosepsis

and bladder stones. It becomes clear that the intensivists do not deem him to be a candidate for the ICU; they urge me to deal with the issue of code status. Vera is backed into a corner, but instead of coming to some acceptance of Alex's precarious existence, she redoubles her efforts to keep him alive. She takes leave from her job to watch over him night and day, sleeping fitfully across three chairs, waking frequently to suction or do chest physio. Some official attempts are made to send her home, but because no one wants to face the unpleasantness of security staff dragging a distraught woman to the bus stop at the hospital entrance, compromises are made.

I struggle with my role in the middle. I understand the futility of Alex's care and discuss this with Vera, the nurses and my medical colleagues. I understand the stress of the nurses having to deal with someone so seemingly unreasonable. But I am also moved by such unfailing love in the face of hopelessness. I can't deny that Vera knows Alex, and that if Vera says Alex is get-

ting sick (afebrile, O<sub>2</sub> sats of 95% and a clear chest exam), Alex gets sick. Vera trusts me and listens to me but she will only hear what she is able to hear.

Birthdays, Christmas, New Year's, anniversaries — the family gathers round to celebrate Alex's life. More pictures are added to the bulletin board. More prayers are said; a rosary hangs from the bed.

Everyone has an opinion: Vera is driven by unresolved guilt or grief or anger; she isn't facing reality and should be pitied; someone should get firm with her; Alex has no meaningful existence; he is unaware of the care and love lavished on him let alone able to respond to it; Alex is just a shell; he should be allowed to "go" with dignity.

Vera has her own opinion about Alex. "Thank God he has life," she tells me. His heart beats and he breathes. She will hold onto that life and dignify it. Vera knows Alex.

**Chris Giles**  
Family physician  
Hamilton, Ont.

## Lifeworks

# The aesthetics of immersion

Janet Cardiff

*A Survey of Works, including Collaborations with George Bures Miller*

May 25 to Sept. 8, 2002

Musée d'art contemporain de Montréal

*Paradise Institute*

June 28 to Sept. 2, 2002

National Gallery of Canada

This mid-career survey of work by Janet Cardiff and her collaborator/husband George Bures Miller was substantially put together by P.S.1 Contemporary Art Center in New York with Carolyn Christov-Barargiev. It comes on the heels of the artists' stunning success as Canada's representatives at the Venice Biennale (the art-world's equivalent to the academy awards), where they received one of three special jury awards for *Paradise Institute*.

Immerse yourself in *Forty-Part Motet: a reworking of Spem in Alium by Thomas Tallis, 1575* (2001). Forty large speakers, propped up on stands (each is roughly mouth-



Musée d'art contemporain de Montréal

**Janet Cardiff and George Bures Miller, 1999. *The Muriel Lake Incident*. Installation multimédia**