

And so I urge you not to waste your time  
On copies; seek instead the primal form.<sup>1</sup>  
Millie Niss: “Derenwenter”

## **First, Create**

By [Martha Deed](#)

A sense of urgency, an insistence on paying attention to the present, and an almost truncated concept of the future marked much of her writing.

Millie was a writer and new media artist: she had been seriously ill with Behcet's Disease for years – virtually a cripple – but her artistic powers were undiminished, and with the help of her laptop and the internet she continued to work and communicate. When she was admitted to the hospital with swine flu, it still didn't stop her writing and thinking. She actually sent off a contribution to a new media project from her hospital bed. She listened to WNYC during the day and BBC4 at night. She couldn't talk, but she kept up a constant stream of e-mails and handwritten notes – to hospital staff, to her parents and to friends online. She wanted to record everything and comment on everything. If she died – which she could always see was on the cards – then she wanted an autopsy, and she wanted the story of her death to be told.<sup>2</sup>

Millie was well aware that, despite internet privacy issues, the internet also allows for creating a persona: If you are chronically-ill with an inflammatory disease marked by unpredictable emergencies in your “real” life, on the internet you can be vigorous and can maintain a consistent presence. You can do this even if you are nailed to your bed for weeks or months at a time.

But it does take planning.

Few of Millie's colleagues were aware of the extent of her mobility problems unless they met her. Millie enjoyed being “normal” and among “the temporarily well” on the net.

As Millie's illness progressed, she returned home for longer and longer periods of time until we closed her apartment in Providence, Rhode Island, and brought her carefully-selected furnishings and books 400 miles west to

western New York where we integrated what we could into our household and combined libraries. I became Millie's hands when she had work to do but couldn't type, her eyes when she couldn't read, her secretary for web and poetry submissions, her medical paperwork manager.

I had closed my psychology practice several years earlier in order to write full time; Paperwork generated by Millie's illness was greater than my entire therapy practice.

But the best part of this collaboration to keep Millie actively involved were our web and writing collaborations – videos, texts, poetry, web art installations. With Millie's technical knowledge, our mutual literary interests, and my ability to follow directions (most of the time), we were gratifyingly successful. Not only did this partnership permit Millie to continue working and publishing, but our work together also provided me with technical training and multimedia opportunities I would never have had otherwise.

It was reciprocal and enriching although accomplished at an unacceptably high price. We had begun working on projects together when she and I lived in separate cities. We could have continued our collaboration without living together. Certainly, we could have produced more work if we had been given more time.<sup>3</sup>

Millie often said, “I have plans.”

I have attempted to follow her plans: First by curating her poetry collection; second by constructing a multimedia fatality review in the style of our collaborations; third by associating myself with the smartest patient safety advocates I can find.<sup>4</sup>

1. Millie Niss. *City Bird: Selected Poems (1991-2009)*. BlazeVox, 2010. P. 82.

2. Edward Picot. Foreword. *The Last Collaboration (Martha Deed with Millie Niss)*. Furtherfield.org, 2012. P. xv.  
[http://www.amazon.com/Last-Collaboration-Not-very-funny-completed-modernization/dp/061564595X/ref=sr\\_1\\_1?s=books&ie=UTF8&qid=1341626540&sr=1-1&keywords=The+Last+Collaboration](http://www.amazon.com/Last-Collaboration-Not-very-funny-completed-modernization/dp/061564595X/ref=sr_1_1?s=books&ie=UTF8&qid=1341626540&sr=1-1&keywords=The+Last+Collaboration)

3. For further information about Millie Niss's and Martha Deed's collaborative relationship and work, see Martha Deed and Millie Niss. From *Fluorescent Cocktails to Pure Cement*. Poemeleon

<http://www.poemeleon.org/martha-deed-on-collaboration/>

4. Safe Patient Project <http://safepatientproject.org/>

Bio: Martha Deed, PhD is a retired psychologist, poet recipient of two Pushcart nominations, and a member of Consumer Union's Safe Patient Project patient safety advocate network. She edited *City Bird: Selected Poems (1991-2009)* by Millie Niss (BlazeVox, 2010) and wrote *The Last Collaboration* (Furtherfield, 2012). Both books are available through Amazon. Her website: [www.sporkworld.org/Deed](http://www.sporkworld.org/Deed) and blog: [sporkworld.tumblr.com](http://sporkworld.tumblr.com).