



# “Bored out of my gourd”: a cancer survivor’s return-to-work experience

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“The cancer had to accommodate my life. My life was not going to be built around this diagnosis.” With those words, Lynn, a 55-year-old breast cancer survivor, expressed her mantra, at play from diagnosis to the present. She delayed her initial appointment with her oncologist because she was scheduled to run a marathon on the same day. Although finding the diagnosis of breast cancer “overwhelming,” it was important for her to get back to “normal” as quickly as possible, including her role as a claims adjuster.

When Lynn was informed that she could resume driving six weeks after surgery, she decided that this would also be an appropriate timeframe in which to return to work, even though her surgical oncologist encouraged her not to rush back. Around the same time that she returned to work, Lynn commenced chemotherapy. It was scheduled every second Thursday, late in the day, so that she only needed every second Friday off work for the four-month duration. Describing her experience at work, she said, “My hair fell out just the day before my second chemo treatment, just as promised by the oncologist” and “that’s when things began to become difficult at work.”

Although she had a wig, she chose not to wear it: “My bald head did not bother me at all.... It is really quite a lovely head, and I was totally, totally comfortable.” But her bald head made others uncomfortable. Lynn’s ordinary work involved interaction with the public, but for the entire time that she had no hair, she was removed from the public eye by her employer. As a result, she was isolated from her usual work activities and given unproductive work that led to severe boredom and a sense of not being valued.

Lynn “begged” for meaningful work, but was still secluded from the public. She described her experience as disheartening and demoralizing, resulting in feelings of low self-worth. At one point, she was able to effectively plead the case that she needed to see a specific client in person. The supervisor acquiesced, and Lynn experienced far more compassion from that client than from her own employer. Sadly, that moment was not a breakthrough for her work

relationships; she continued to have to plead for meaningful work.

Although many people within her work environment were supportive, the direction from management was that she was to remain out of the public eye. Lynn attempted to self-advocate, to little benefit. She repeatedly expressed her dissatisfaction to her supervisor and management, imploring at one point, “Please understand that this return to work is as demoralizing as the disease, and is that the way you want to do it?” The irony concerning the fact that the focus of her employer was on returning injured or disabled clients to work was not lost on her. Lynn’s experience was that there was no investment in helping “one of their own” return to work in a meaningful manner. Eight months after her return to work, Lynn’s hair grew back, and although her self-advocacy had resulted in small victories along the way, it was not until then that she was permitted to interact with the public and to resume her efforts to help them return to their own meaningful work.

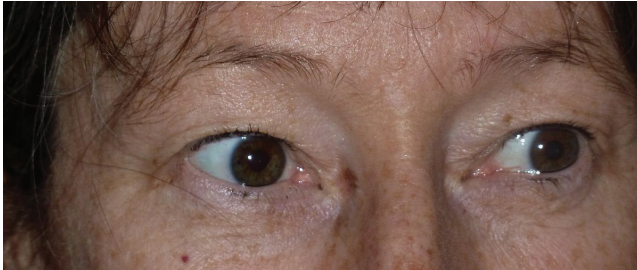
Lynn’s story was shared through her participation in a photovoice (qualitative) study exploring the experiences of 10 cancer survivors during work return and maintenance. The goals of photovoice include<sup>1</sup>

- enabling often marginalized participants to record and reflect strengths and concerns,
- promoting critical dialogue and knowledge about important issues through discussion of photographs, and
- reaching policymakers.

In the study, participants were asked to produce and discuss photographs depicting meaningful aspects of their experiences of the intersection of cancer and work. The study received ethics approval from the University of Ottawa’s Research Ethics Board, and all participants, including Lynn, provided their informed consent to participate, as did any third-party individuals included in the participants’ photographs. Three of the more poignant photographs

shared by Lynn follow. Each photograph represents a meaningful aspect of her return to work after cancer. Lynn describes, in her own words, the intended meaning of each photograph.

### Averted Eyes



You're seeing a middle-aged woman's eyes averted... [Middle-aged women] unwilling to either confront or accept what is in front of them. And at that point in time, it was ... a woman without hair... I was referred to as the "bald lady" in many instances, but I really was just a woman without hair. I found that women in my age group ... had the greatest struggle with it. The people who didn't were like the kids who were like 18, 20, 21. Now—God love them—they're all tattooed and pierced everywhere, right? So ... everybody has a unique look. So for all of those people, none ever, ever averted their eyes or anything like that. But women my age did. Men tended to stare a little bit. Probably wondering why I wasn't covering my head. Women may have been wondering that as well, but they averted their eyes.... I met many averted eyes, both at work and in the community.... Some people might have thought, "Oh God, that woman looks horrendous!" ... So it could have been that, right? ... Physically, there was something very unattractive about a woman without hair.

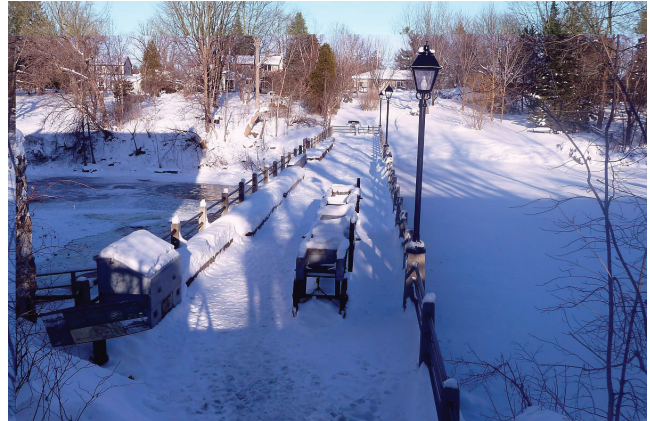
### Human Strength



A tremendous amount of human strength is required to [return to work] on many levels.... Mental strength, emotional strength, physical strength, spiritual strength, all of it....

Strength coming back to work wasn't so important. Strength enduring the return to work was much more important because it wasn't a constructive experience. So it took a tremendous amount of strength on all levels to endure it.

### The Bridge



How do I get to the other side? How stable is that bridge? What is that bridge made of? How long is that bridge? Is there anybody else on that bridge? What's under that bridge? How do I get to the other side? Can I go all at once? Do I have to go one step at a time? Am I going to go backwards on that bridge? Can I run across the bridge and make it quickly? Do I have to walk? Do I have to crawl? ...

I was at ... the foot of the bridge, and I had no idea how long [it was] or how to get to the other side given the obstacles that were in my path.... Oh, I knew how to do it. I knew. That wasn't the issue. The issue was, I needed the blessing.... I knew how to get across, but I needed their authorization. I would have been very happy had they been prepared to go across the bridge with me.... Follow me across the bridge.... I would have been very, very happy to have led them across the bridge too, but they didn't show up.

### The Morals of the Story

Lynn's narrative was selected for this article because it highlights challenges that may be experienced by cancer survivors in their efforts to return to work. In Lynn's case, the challenges occurred despite her employer being well-versed in return-to-work issues. Like other participants, she identified her experience as one of uncharted territory for her employers. Although they had experience with other cancer survivors as employees before her, those individuals took more time off work and returned once the physical stigmata of the treatments had largely resolved. They simply had not previously been faced with a woman without hair in their work force.

Lynn's story highlights the need for a much more open-minded and accepting approach in this domain. She cautions other survivors to be prepared, because she feels that she was ill-prepared for the struggle that other people had with her appearance, even though she herself was at peace with it. The strength to return to, and to maintain, work activities is often considered within the physical realm; however, under less-than-ideal circumstances, strength of character and spirit as well as psychological and cognitive robustness are also needed. In some cases, they are the dominant challenges, as in Lynn's case. Lynn would encourage all employers to note that the bridge to a successful return to work is wide and that the optimal way to help a colleague in their return is to walk alongside them.

For health care professionals, several considerations are highlighted. Survivors report a lack of available supports to assist with return to work, leaving it to survivors to use a trial-and-error approach, which underscores the need for an interdisciplinary approach to survivorship, including the role of occupational therapy in the larger context of cancer rehabilitation and return-to-work efforts. Such intervention might assist with functional and vocational resumption for survivors, facilitate employer education, and ease communication between survivors and

employers, with the goal of optimizing successful work reintegration.

Lynn has been cancer-free for six years and continues to work with the same employer she has had for the past 14 years.

### CONFLICT OF INTEREST DISCLOSURES

This research was supported in part by the Canada Research Chairs Program. The authors have no financial conflicts of interest to declare.

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