BC/AD (BEFORE CANCER / AFTER DIAGNOSIS) A POETIC TIMELINE OF ILLNESS FOR PATIENTS AND HEALTHCARE PROFESSIONALS

by

Kimberly Darcy Anne Taylor

B.A., Vancouver Island University (2007)

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Abstract

In December 2005, I was diagnosed with aggressive, invasive breast cancer. A

former competitive athlete, I was shocked but also relieved I was sane. I wasn't dramatic

or attention-seeking, a hypochondriac, or lonely, as my doctor had admonished for five

years. I really was really sick. And to think it was my dog who had proven me right.

Throughout 2006, I underwent two surgeries, a systemic infection, chemotherapy,

and then radiation. I lost all my hair but missed my eyebrows the most. I ballooned like a

blowfish. My eyeballs became sandpaper. I contracted a staph infection and was the

ugliest Me I could've imagined. But I survived.

This thesis is a poetic and verse self-narrative of 2006. Using theories of

performance, art therapy, autoethnography, Arts Based and transdisciplinary research

(among others), I chronicle the hardest days and nights I have ever known.

I am surviving.

Note: to view the performance of my Thesis Defense, please visit YouTube at https://www.youtube.com/watch?v=cuhu0Xz8g9c

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YouTube

https://www.youtube.com/watch?v = cuhu0Xz8g9c

Performance of Thesis Defense Presentation "BC/AD (before cancer/after radiation): A Poetic Timeline of Illness for Patients & Healthcare Professionals"

Dedication: For every day, I am blessed. This thesis journey includes too many people to thank individually and my heart is full! I can't thank 'my people' enough!

First and foremost: Thank you Dr. Robert Budde for urging me onward, forward, always.

Respectfully, to my parents: I don't know words enough to convey my love and thanks.

To Gloria: You really are Glorious, Gloria, and you were elemental to my survival. Thank you for caring, for whisking me into your own home when needed, or when my home was full of chemical fumes lifting from the basement workshop. You listened, made me laugh, and mothered me. You arranged a loving environment for me during my radiation. You are amazing.

To Crystal: I'll never be able to make beet borscht as yummy as yours. Thank you, thank you, thank you for keeping me fed when everything else wouldn't stay down. What an angel!

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To Liza: Your honesty and candor were so refreshing, and you provided me with alternative perspectives and possibilities. Your belief in me never waned or wavered. You shared your soul and your bright Marilyn Monroe laugh... O, my Dear Friend!

To Shizuko: I admire you in a very special way. Your quiet voice, your courage, your patience... thank you for traveling so far to see that I would survive. Those few hours in my dining room will be a treasured memory, forever.

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And to Freeman: Rest in Peace, ManMan, my friend, keeper, and Hero. I miss you daily.

BC/AD

before cancer/after diagnosis

Introduction

Whenever someone asks my age, I get it wrong by a year. It's because 2006 was a nightmare during which I was not *really* living so, without thinking, I literally subtract one orbit of the sun from my age in an attempt to dilute my memory or deny somehow that 2006 ever happened.

On December 22, 2005, I was diagnosed with aggressive, invasive breast cancer. The diagnosis part had actually begun in October, when my puppy Freeman jumped up against my chest for perhaps the 100th time since he had become part of the family just three months earlier. A typical puppy, Freeman was energetic and inquisitive, but no matter who he was greeting, he was always polite and distinctly paws-off. It was the complete opposite with me however, and this particular October day, he did his usual: with his front paws together, Freeman launched himself up onto his hind legs without warning and hit me in the right breast. Because it had become his habit to jump up on me like this, or to walk up to me as I was sitting on the couch and raise one paw to strike me, I believed he was being willful and trying to claim Alpha dominance over me. Freeman often caused me physical pain, and I had become so frustrated that I had been discussing finding him a new home.

On that particular day however, my A-cup breast instantly ballooned into a cantaloupe sized, searing boob. Alarmed and deeply in pain, I phoned my doctor and pleaded for a mammogram and companion ultrasound. Seven days later, I called my doctor again, but this time I demanded a mammogram and ultrasound. I had spent a full

week with brutal, non-stop pain and excessive swelling. I knew something was terribly wrong, why was I not being taken seriously? I cried and shouted into the phone until I was promised the appropriate referrals and appointments, and four days later, laying on the ultra-sound table, I saw four (*O my God, four*) cloudy masses on the ultra-sound screen. Four had never been a good number for me, and my blood instantly cooled. I knew it was Cancer, and instinctively knew it was very, very bad. I had been complaining to my doctor about that breast for a number of years. I had had one small lump removed five years earlier, after stepping out of the shower one morning to realize the nipple expressing a bright streak of blood down my body to pool on the linoleum floor. The lump had been removed, but the breast had been bothersome ever since; how many times had my physician told me to relax, that I was simply imagining discomfort? Perhaps I was depressed (here's a prescription for Zoloft, here's a prescription for sleeping pills), or could it be that my marriage was unhappy and I was just seeking outside male attention and/or sympathy?

I was not fooled that November afternoon when the ultra-sound technician told me that he was 'just going to call another, more experienced technician' to help him deal with what he called a technical issue, a problem with his machine. It was so obvious he was lying—he too saw those four cloudy masses—and that the image on his screen was not good. I stopped him before he went out the door. "I haven't had breakfast, you know. I have an empty stomach. I can go into surgery right now, you know..." My voice was strangely calm, abnormally lower in tone. I sounded miles away from myself.

It took less than five weeks for me to undergo a swift and permanent change: what I had previously perceived as *healthy*, was in fact *ignorant*. In just weeks, I had two

serious surgeries and a horrible post-operative infection, and became an acute-care, chemotherapy patient with a bad prognosis. By January 6, 2006, the date of my second surgery (a radical mastectomy on my right side), my perceptions and all I associated with what life could and would and should be, had turned pink. Breast cancer was suddenly everywhere. In fact, I was only one of 21,000 Canadian women going through the nightmare that year. I was a fit, vibrant, energetic woman in my late thirties, a former professional-competitive cyclist who had held a proud ranking in two countries. But I was completely unaware that there are indicators regarding breast cancer risk, and that I exhibited a handful of them. I had never had children or been pregnant. I went through puberty and developed very late. My monthly periods had always been abnormally painful, and my flow quite light. My hormones had always been out-of-whack when compared to my peers. Due to my athletic lifestyle, I survived and flourished on a protein-rich diet. And finally, I am an Ectomorph body type. But wasn't I super-fit? Wasn't I young, and strong? I had not invited or sought ill-health. For years, I had exercised diligently, eaten as organic as I could afford, cooked healthy, low-fat meals, got counselling, and lived simply. I was doing everything 'right' so shouldn't I be completely healthv?

It was confounding in many ways. However, I learned a hard and mind-shattering, indisputable fact: Cancer is a volatile force, striking whenever and whomever it wants irrespective of age, religion, gender, demographic, intelligence. Lifestyle can of course be a factor, but no matter what any self-help author may suggest or try to sell (yes, Louise Hays, I mean you), no one chooses Cancer. It is as non-discerning, surprising, and violent as shrapnel. That terrible year, nearly 6,000 Canadian women were killed by breast

cancer. *Six thousand*. Although I never asked *why me?*, I was astounded that such an important and monstrous battle had been going on in my body without my knowledge, without my permission. I didn't fear death nearly as much as I feared missing important things; what came to mind immediately were my nieces... if I died, I would never see them in their wedding dresses, never meet their children. From diagnosis forward, I would wonder daily if I was one of Canada's 6,000.

The first thing I had to take care of, in order to devote myself to fighting Cancer, was to withdraw from my Bachelor Degree. I was pursuing a double-major in Creative Writing and English, in third year of a four-year program, earning high grades and enjoying the post-secondary learning experience. Although I never cried about my diagnosis, I cried openly when I had to quit my studies. I had pursued academia late in life and was facing the possibility that I may never earn a degree; I suddenly wanted my degree more than I could stand.

Throughout 2006 and during my primary treatments however, I kept my academic dream alive by continuing to write. Two of my professors were gracious enough to challenge me to continue enrolment in directed study courses they designed just for me. One course was Longform Poetry (instructor Stephen Guppy), the other, Creative Fiction (instructor Marilyn Bowering). Difficult as concentration was for me, these courses were foundational to my sanity. Stringing words together offered me a tenuous and delicate life-line, preventing my losing sight of the woman I had been BC (before chemo). But I was incredibly fragile; 2006 was the beginning of my AD (after diagnosis) life when I struggled through what I call my "aggressive treatments." My surgeon had reviewed my

medical history and discovered that the lump I had removed from my breast in 2000 was in fact cancerous, and that I should have received "at least radiation" at that time.

To this day, it mystifies me that both my GP and that original specialist could apparently not read pathology reports correctly. I will forever be shocked that not one but *two* professionally recognized doctors somehow made such a mistake. The awful outcome of their errors was my Oncologist telling me on the phone at eight o'clock that New Year's Eve that I only had six months left. My situation was incredibly urgent. Dr. Olivotto said he hoped I would spend my "last six months trying to get through the eight rounds of chemotherapy" he was prescribing and that if I did, he foresaw radiation treatments in order to ultimately survive. He informed me that I had one of the best breast surgeons in the country on my side, and that together, the two of them would do everything they could to help me. Before I hung up the phone, I told Dr. Olivotto I needed full disclosure about my prognosis, because the next time I saw his name on my call display, I would likely be unable to force myself to pick up the phone. I remember that call as being entirely scary and mind-blowing, but I also remember hanging up the phone pleased that Dr. Carr and Dr. Olivotto were my doctors.

More than anything else, I knew that I was living in the best medical-now possible. Survival would be more possible due to the fantastic medical and technological advancements that were available to me. My surgeon and my oncologist were already working together to change my life for the better, and I could not have asked for a more professional and passionate pair of practitioners.

It was a very, very life-and-death battle I was in, and that whole year (2006) of treatment was horrible. Whenever I had the strength, irrespective of my cognitive

function or lack-there-of, I wrote. Poetry was the thread I clung to, even as I returned to full time studies the very day after I my radiation treatments were completed. But I had no choice really; I was being hounded, badgered, and bullied by my disability insurance company, whose representatives called at least twice a week for that full year to inquire when I was going to go back to work. How was I feeling? Once my aggressive treatments were completed, their questions changed to a far more direct and demanding tone: How long exactly did I expect them to pay me a monthly amount, since my treatments were now *over*? I couldn't take the added stress, becoming terrified of the ringing of my home phone, and begged them to stop bothering me. Miraculously, my monthly insurance payments stopped. I didn't have the energy to fight back, so my only income disappeared.

Student loans was virtually no better; for four months prior to the conclusion of my treatments, they had been withdrawing loan re-payments directly out of my bank account. This, despite my having faxed them my medical files and loan-forgiveness paperwork over and over and over, despite having no income outside of the disability insurance which I used to buy groceries and anti-nausea medication. Though my reliance on those expensive little pills (approximately \$38 per pill) had ceased immediately after chemo had finished, I had to force myself back into life as quickly as possible before I had to also claim bankruptcy.

I lost almost the entirety of my energy during the ensuing years of adjunct therapies. Tamoxifen was a five-year, daily commitment; a small pill (this medication was covered by medicare) with massive impact. I had initially tried to avoid it, but a survivor who worked in the English department at my university begged me to take it, weeping that Tamoxifen was a gift I could not afford to ignore. She had known women

who had not had the same luxury I was being offered, and those women had died when their breast cancer recurred. *Put your fear aside, and take the Tamoxifen. Take it.* Now, I am thankful that she shared such hard truth with me, and am deeply thankful for her candor and compassion. Side-effects of Tamoxifen include pronounced chemo-brain and what my oncologists cautioned would be 'accumulative fatigue' (boy, they weren't joking!) and the six-plus years of treatments felt like a really long, ugly time.

Ten years along in my AD period of life now, I've compiled a series of linked poems as a chronicle of the experience that cancer and its treatments were to me and could well be for others. This is my thesis. My intentions for this project are primarily two-fold. First and closest to my heart, it is my mission to understand my own being relative to my surviving a near-death illness. In so doing, I wish to provide a manuscript which bears testimony to everyone dealing with Cancer that no one is alone, that being confused is not a sign of weakness, that no one deserves the destructive, frightening tidal wave that Cancer is, and that they CAN survive. In the words of Heewon Chang, "In a culturally "congruent" society, relating to others may not be such a daunting task. Others are merely others of similarity; thus, understanding others may easily begin with knowing and affirming self" (Autoethnography as Method, 28).

Secondly, I consider my manuscript a direct challenge to health care providers, practitioners and professionals. I would like my collection of Spoken Word and page poetry to inspire members of the Health Care Industry to assess and re-calibrate their model of care, to hear the misgivings of patients when they are assessing those patients, to learn from and be kind to all patients, to be non-judgmental with questions, concerns

and experiences of both the patients and their care-givers/family, and to be receptive to and cognizant of each and every patient's identity and intrinsic, unique value.

This paper *is* my experience, and therefore derives from and reflects my belief that very foundational and established hierarchical structures exist within professional Health Care in our developed world. I found it interesting that the doctors and specialists I dealt with both immediately before and during my illness¹ were *male*; the only women I encountered were the Mammography and radiation technicians, and the chemotherapy nurses (Cathy and Margie and the other nurses in the Nanaimo Hospital Chemo Unit were vital to my care and were all Angels with capital As). I received excellence of care and attention during chemo, and to this day I weep with gratitude when recalling the amazing, invaluable nurses without whom I wouldn't have made it. Very early on though, I noted a lack of female specialists, Oncologists, surgeons; women did not occupy what I had been enculturated to consider the 'power' positions in healthcare.

My illness experience incorporated what I perceived as dismissal as an underling, unknowing patient, but also as a female in an industry which appeared male-dominated. In my case, the placations of my physician were somewhat believable because the alternative to *you're over-reacting, you're fine, there's nothing wrong with you* was terrifying. However, Patient-Centered Care is a model I now advocate for many reasons, primarily the ability to save lives while simultaneously eroding fear, and therefore the potential of entrenched perceptions, needless hierarchy, and sexism.

It is intensely unfortunate that my physician discounted my intuition that something was wrong with my body. His presumption nearly cost me my life—so it is

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¹ 2 GPs, 1 specialist, 3 Anesthesiologists, 2 Oncologists, 1 Breast Surgeon ,1 'wire-location' specialist, 1 Radiologist, 1 MRI technician, 2 Ultrasound technicians.

logical that I am now intensely adamant that no medical professional has the right to dismiss a patient's instinct. After all, sometimes instinct is all a patient *has*. I admit I feel like the poster-girl for self-protection and self-advocacy when it comes to medical care, but it is a position I'm willing to accept. I am upright. I have hair. I also have the ability to string sentences, although I no longer have the patience or mindset to back away from what could be a verbal confrontation or a challenge. Only I can champion my Self and my body, and such self-empowerment demands that I ask hard questions, learn, engage, and be as fully involved in the care I am receiving as I possibly can be. I believe that this attitude is one of the most important reasons I have survived.

My interpretation of health care, though based on my own singular experience, finds support and theoretical substance in the work of Norman K. Denzin. In *The Qualitative Manifesto* (2010), Denzin names my style of enquiry and 'research' as an evolving and legitimate qualitative method, with me acting as a specialized "bricoleur" (13) and someone who "work(s) at the center and the margins of intersecting disciplines, from communications, to race, ethnic, religious and women's studies, from sociology, history, anthropology, literary criticism, political science, and economics, to social work, healthcare and education" (15). Heewon Chang quantifies the vital sharing of knowledge: "understanding of others begins with genuine encounters with them through which insider perspectives are gained" (Autoethnography as Method, 27), and therefore my self-narrative can be a positive catalyst within healthcare practice. Just as Chang summarizes, "the study of other self-narratives helps [readers] compare and contrast their lives with those of self-narrators. This cognitive activity of compare and contrast engenders self-examination and self-learning" (Chang, 41).

Analysis and change within medical care has already begun, with several Canadian Health Authorities and institutions dissecting their long-held principles of delivery of care and undergoing an innovative shift from a stringent delivery style towards holistic, full-spectrum care.

The Canadian Foundation for Health Care Improvement (Ontario) ² is leading initiatives to combat wait-times, deliver safe care, and increase patient satisfaction, while both Alberta and Saskatchewan health agencies are researching patient-centered care strategies as measures by which to create positive, recovery-focused care models. Personnel in direct contact with patients are being empowered to create *solutions* which reduce costs and streamline institutional processes for both patients and care providers³. Within these pursuits, we see a commitment to transfer knowledge into appropriate and meaningful practice, from new technologies through to non-discriminatory care, resulting in increased productivity and reward within the professional workplace.

These three provinces are categorically redefining "patient" to include the patient family and non-medical care-givers, and then implementing mission statements which capitalize the importance of Patient-Family Centered Care (PFCC). This is a bold and dynamic move, signally a new consciousness towards individual patients. Expanding the definition of 'patient' is also what I consider the first step towards *a process* of severing reliance upon the entrenched traditional power structures within our medical industry. Furthermore, such changes in ideals and processes advocates more fluid communication between professionals of various branches and disciplines of healthcare, a process called

² Data paraphrased from www.cfhi-fcass.ca/home.aspx;

³ Data paraphrased from both albertahealthservices.ca and www.health.gov.sk.ca

Patient/Patient Family Engagement. Such changes, steps and ideals essentially introduce an ideal of collaborative practice(s) between health care professions.

Chang addresses this very timely situation, speaking to the large-scale benefits such changes can produce and enhance:

autoethnography is becoming a particularly useful and powerful tool for researchers and practitioners who deal with human relations in multicultural settings, such as educators, social workers, medical professionals, clergy and counselors. The benefits of autoethnography lie in three areas: (1) it offers a research method friendly to researchers and readers; (2) it enhances cultural understanding of self and others; and (3) it has a potential to transform self and others to motivate them to work toward cross-cultural coalition building. (52)

Spoken Word Poetry

In a movement that harkens back to cultures from every continent, Spoken Word Poetry is an emergent thread to oral customs and storytelling, not to be undervalued or dismissed. Spoken Word Poetry (SWP) or Performance Poetry is understood as the stories of common people for the masses, but its ability to promote empathy literally promotes listeners and practitioners to cultivate a new consciousness with sensitivity towards an issue, and/or societal change. It is a consolidated communication tool capable of inspiring critical thought and structural social changes with the use of poetic devices (story-telling, rhyme and slant rhyme, imagery, metaphor, musicality, presentation, language and sound, etc, etc.) to support effective listening and thorough *hearing*. Canadian SW Poet Sheri-D Wilson (aka: The Mama of Dada) submits that SWP "is the oldest form of poetry" (The Spoken Word Work Book, 1). Wilson states that resurgence of Poetry transports us "back to its root, or its oral origin and thus this new form has returned the voice of the people to the people." Wilson also clarifies SWP realm as:

jazz, dub, hiphop, sound, slam, folk, mystic poets, and storytellers. It emulates the beat of the street...includes the body, as memory vessel, and resonator. Gesture is an important aspect for punctuation and jubilation. Spoken word poetry is oration with rhythm, metre, and repetition, and often involves humour and social commentary. (1)

Recognized as a growing art-form, the thrust of SWP is its community-minded focus: stand-alone performance pieces combine various vernaculars with elevated, stylized lexicons to invest in dialogues of social conscience and change, highlighting devalued discourses and previously taboo subjects with bold inquiry. Essentially a completely heuristic process, this poetic genre becomes immediately more than just poetry. As James Haywood Rollings, Jr. asserts "arts-based research (ABR), like all research, is theory-building... [and] involves the 'contemplation' or 'speculation' of natural laws and phenomena of life" which are furthermore "a representation of experience so that others may also acknowledge and understand" (Arts-Based Research, 1). Accordingly, Rollings, Jr. defines the importance of such: "when a theory is built and deployed as heuristic device, an abstract and internal sense of a person, place, event or thing may then be *further* ideated... stocking our shared warehouse of assorted ideas about the human experience... further shaping our personal ontologies" (2). Intertwined with and augmented by the power of live performance, Spoken Word becomes a tangible, recognizable art, but also a theoretical tool, camouflaging social science, hypothesis, consciousness, and solution-generation within entertainment.

Competitive literary venues showcase a form of Spoken Word Poetry called "Slam" poetry which has evolved into a linguistic Olympics, the world over. National Slam teams train for events for months in advance, and team membership is an absolute plume in any poet's cap. The World Cup of Poetry occurs annually in Paris, while the

Nimbin Poetry World Cup is the Australian equivalent. Countless events occur worldwide and poetry organizations range from private, small scale features to immense, officially governed festivals and competitions, oftentimes boasting 500 competitors in one category, with even larger audiences. No longer attributed to the intimate and smoky, American café-culture of the 60s, Spoken Word Poetry currently boasts mainstream audiences through websites like You Tube, Button Poetry, Def Poetry Jam (filmed in a 'black' New York poetry bar, this HBO show aired from 2002-2007) and numerous other agencies of access on which performers like Shane Koyczan have garnered literally millions of views from around the world. Poetry has been redefined as a modern (and 'cool') vehicle of not only art and critical thought, but of prestige and virtual stardom.

That both the art and the attitude of Poetry has changed in recent decades, transforming from a dreaded unit in high school into a highly marketable, fast moving and exciting world, is inarguable. It needs noting however, that two sub-cultures or subgenres interweave modern SWP, and that these two genres have become recognized art forms in their own right.

Due to its prominence world-wide, I will assume Rap (music) needs no explanation, no background theory: I invite no discussion on this genre as this thesis is about poetry *without* background music. Slam Poetry however, may require further context. Poetry as a viable, appealing and applicable communication and education tool within society, is a transformation many poets attribute to Slam. Invented in 1984 in Chicago by construction worker Marc Smith, Slam Poetry's philosophical intent was to remove the elitist stigma attached to poetry, and deliver entertaining, concentrated stories to common-man audiences without stuffiness, remorse or apology. Subject matter ranged

from guttural, heart-wrenching, inspiring, chilling, and controversial—impact and profoundness were encouraged and laudable. Slam Poetry is competitive, a sport per se, of literary, grammatical, poetic, and imagistic sparring. Competitors are evaluated by a panel of judges usually comprised of members of the audience, through a series of heats or rounds, like boxing. Competition rules are universal:

- 1. memorized works earn/receive better ranking; each poet comes prepared to multiple 1, 2, 3 and 4 minute-long poems
- 2. time limits are serious: points are deducted for every extra 10 seconds
- 3. props, costumes, and/or accompanying music are prohibited
- 4. audience reaction factors into a poet's ranking
- highest ranking poets move up in rounds, competing for an overall
 Champion

Slam Poetry and its events took the sub-cultures of North America by storm, and spread onto other continents with firm conviction, creating a borderless landscape in which modern poetry and modern poets have become recognizable icons within pop culture and mainstream society. A former Slam champion, Canadian poet Shane Koyczan has collaborated with national opera houses, and performed with symphonies. His verses have been used in television and radio commercials and campaigns. Like SW poet Taylor Mali, Koyczan is privileged to receive invitations to perform and speak around the globe; he delivers TED talks, he signs autographs and is becoming a familiar name in many households, Canadian and international. Poets like Mali and Koyczan began as closet poets and story-tellers, moved into and through Slam Poetry venues and championships, and matured into respected mega-performers and purveyors of societal change.

Origins of Spoken Word and Oral Poetry

How can the precise beginnings of spoken histories and oral teachings be claimed? Critic Maisha Fisher isolates the origins of Spoken Word Poetry towards Black diaspora within America and certainly venues like Def Poetry Jam support that claim. Fisher asserts however that SWP is the evolutionary product of communications developed and utilized by slaves, with slaves. I step back from the racialization this suggests to me, confounded as I am that SWP's *origin* can be claimed by any one culture. Def Poetry pioneered an unstoppable resurgence of poetry in our current era, launching hip hop artists and unknown writers alike into a fresh scene of activism and entertainment. It was a pivotal awakening of both poetry and social thought. Well ahead of Def however, one of the greatest orators of all time enacted monumental social changes with his words. Martin Luther King Jr. was one of the most pivotal men of the Twentieth century. An excessively passionate and talented speaker, his "I Have a Dream" changed North America, proving the intense power of words, reaching into the political milieu to disrupt inequality and rock education and public perceptions by awakening the world to socio-economic barriers that were unjust and fallible. King was a brilliant activist, an icon who moved the world with poetic discourse. Humbly, I consider King a Spoken Word Poet of immense proportions.

However and with no disrespect, I believe the true root of this art goes back to the origins of human speech itself. In 2014, I attended the prestigious Banff School of the Arts for their SWP Residency program. My cohort boasted 15 participant poets from literally around the world, with faculty from three continents; we were a diverse, global group. Of the four faculty (Tanya Evanson, George Elliott Clarke, Emilie Zoey Baker, and Jean

Pierre Makosso), three were of African descent, although all had testaments of modern poetry which mirrored or included the beliefs of Fisher. Clarke spoke to the SWP craft having expanded during American Prohibition within the speak easy culture, eventually expanding beyond 'colour' to be art and entertainment. Our textbook for this residency program was "The Spoken Word Workbook", edited by Sheri-D Wilson, who stated SWP is poetry and knowledge "presented in the lingo of the people for the people" (1). Conceptually, this art logically originates in underground movements necessitated by oppression, violence, racism and inequality, as evidence in how it is performed, written, and created *now*.

As entertainment, SWP is owned by no singular demographic, no one culture, no sexist identity, and whether this is due to a diverse and ancient root system in many different continents and/or cultures continues to be a vibrant topic of discussion amongst poets. The lineage of SWP is as a purveyor of social change and interpersonal learning. Fisher cites what she terms PLCs (participatory literacy communities), very like the underground venues of the past where intergenerational poets "exchange ideas and lived experiences" (139) to inspire broader and more robust conversation or social criticism.

Prior to the written word and the printing press, memory played a huge part in the keeping, passing and preservation of histories, stories, knowledge, folklore, and culture itself. Irrespective of the language, poetic tricks have helped memorization and retention. The ancient Anglo Saxon epic sound poem "Beowulf" (the oldest copy is dated approx. 1000AD), is quite venerated in our modern world, boasting inclusion in such popular modern realms as video games, feature films, and comic books. This sound poem would

have been memorized by ancient performers and is heralded as both a literary and historical work, which attests to the staying power of poetry.

Wilson's view of SWP's history is infinitely broad, and is a view I completely share. "Some claim the oral tradition originated with Homer, continued through Shakespeare, Dadaism, Surrealism, and into the Beats. This is true for those of academic persuasion, but the roots of the oral tradition originated in a diverse variety of cultures: African culture, Caribbean culture, North American Aboriginal culture, Islamic culture, Celtic culture, and every culture known to humankind—spoken word is the oldest form of poetry" (The Spoken Word Workbook, 1).

The contemporary resurgence in the appeal of recitation poetry and Bricoleurs (what Tanya Evanson called "Griots") is evidenced in possibly unlikely circles of society. For example, Paul Harvey's "Farmer" (the narrative used in Dodge's 2014 Superbowl ad) to Taylor Mali's 2003 release and subsequent publication/book "What Teachers Make" (credited with inspiring thousands of people around the world to become teaching professionals), and Shane Koyczan's "We Are More," performed live during the opening ceremonies of the Vancouver 2010 Olympic games. Koyczan must be the first poet in the history of mankind to have such an astounding sized audience: a live/in-person crowd of tens of thousands, and a television crowd of over 32 million⁴! The Spoken Word genre of poetry has literally become *enormous*.

Performance and Audience

This thesis will employ original works of poetry in a specific "social audit" (Hill et al. 1998) context regarding the potentially oppressive power doctrines prominent in

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⁴ Statistics sourced from http://www.hollywoodreporter.com

health care fields. Poems are meant to also address the resultant voicelessness, whether perceived or actual, of the 'other' (aka 'the patient') to effectively culminate into a testimonial and handbook for *other peoples* in health care. In this thesis, I define 'other peoples' as acute-care patients and their primary care-givers. "The term "others" generally refers to existentially different human beings—those who are other than self," writes Chang (Autoethnography as Method, 26).

In the theoretical framework of this thesis, I accept Chang's expanded categories of 'otherness' as well: Others within one community, comrades with comparable values, ethics and standards are "others of similarity" while enemies with irreconcilable differences of any kind are "others of opposition." The middle ground is "others of difference," where the difference itself can become, through empathetic understanding, an interconnectedness between strangers or 'others' of any type" (26). In this thesis, cancer patients are my others of similarity, while hierarchically-based doctors are others of opposition, and health care practitioners willing to listen are others of difference. Within this context, I hope my poems (what Chang would call my self-narrative) will become vehicles of empathetic understanding which bind together as many 'others' within health care and health experience(s) as is humanly possible.

The validity and value of Performance as a proponent of knowledge, experience and validity is captured succinctly by Peggy Phelan as a form of "consumption" with "no left-overs, the gazing spectator must try to take everything in. Without a copy, live performance plunges into visibility – in a maniacally charged present – and disappears into memory, into the realm of invisibility and the unconscious where it eludes regulation and control" (Unmarked – the Politics of Performance, 148). Knowledge-sharing of this

type is the Bricoleur's and Griot's gift and reality. However, Phelan also cites the down-side of physical performance, speculating it is inherently less static and therefore less tangible and contemplative compared to arts like photography or film: "Performance is vulnerable to charges of valuelessness and emptiness" despite its power of revaluation and its "distinctive oppositional edge" (148).

Autoethnography

According to Denzin, autoethnography and performance offer a balance to previously stringent one-sided methodologies of both investigation and scientific research. "We need a performance studies paradigm that understands performance simultaneously as a form of inquiry and as a form of activism, as critique, as critical citizenship." He states further that the "academy" of quantitative research needs to be shaken from its stronghold. "Today there is no solidified ethnographic identity... critics and advocates alike share a commitment to social justice... Qualitative research can be used to advance human rights agendas by bringing about healing and social reconciliation" (The Qualitative Manifesto, 17).

This manuscript, although decidedly qualitative in thrust, hopefully transcends mere personal expression, fulfilling my ideal to facilitate the following:

- a method of expression patients/family, care givers and professionals can utilize
- a vehicle through which to promote and stimulate transparent communication between key stake holders, services, and health authority institutions and branches

- 3. education and communication devices in the context of social-audit, and
- 4. the distillation of the voice of the 'Other' (patient and patient-family) to health care professionals and practitioners

Theorist James Haywood Rolling Jr. defends alternative methods or non-quantitative methods of enquiry, stating succinctly, "Not everything that is knowable or worthy of knowing in human social worlds can be captured adequately within mathematical or statistical frameworks and scientific theoretical orthodoxies," adding "there are so many kinds of knowledge, it is no surprise that some of it is *best* conveyed artistically" (Arts Based Research, 57). Rolling Jr's stunning revelation that the very process of theorizing is *creative* situates performance poetry and other arts as verifiable research methodologies and measurements. "By the time the researcher or artist arrives at an emergent theory, their work has already established its own rigorously resolved internal validity" (49) and wonderfully, Artists like myself become robust purveyors of knowledge, who expand knowledge when we deliver our art "into the common cultural store to prod further social inquiry" (49).

Malchiodi delves into the possible benefits of patient-driven art projects like my thesis, asserting [they] can "inevitably symbolized hope and possibility for recovery of all cancer survivors" (Art Therapy and Health Care, 331). Spoken Word Poems function as personal declarations and in my case provide a forum to share my health experience in an empowering way "outside the hospital or clinic" so I may "provide education on the relevance of a particular disease, its psychological impact on the individual and family, and challenges encountered during treatment" (331). My idea that my own patient art-based research is necessary to change medical care is validated by Piko and Kopp's

statement: "medicine should become an integrated scientific field, at the crossroads of the natural and social sciences, needing a transdisciplinary approach" (Essentials of Transdisciplinary Research, 84).

I submit that there exists an enculturated, historical and relatively unchallenged posturing of doctors and other professional health care providers as elite, all-knowing individuals. This positioning has resulted in a Health Care delivery system which propagates a dynamic of expected voicelessness for patients, patients' family members, and their personal care-givers. Over time, this hierarchy has effectively discounted those not defined as esteemed practitioners and/or Doctors, and therefore dismissed a very real and potent specialist regarding the quality of care being delivered—the patient's experience as a specialized, educated consumer of professional Health Care. To summarize Leavy, who has quantified and categorized my method of enquiry as Community-Based Research (CBR), combining scientific and patient knowledge can effectively increase the usefulness of the knowledge conveyed to learners, and "generate higher levels of commitment from all [research] partners" (Essentials of Transdisciplinary Research, 95).

Spoken Word poetry can be offered to the full spectrum of persons in health care environments through various formats from performance to seminar to communication workshop (for example), to promulgate a new era of inclusive communication, treatment practices, and wellness. Distilling the many stories of health care experience to Health Care practitioners and professionals encourages expansion(s) within Health Care and its practice, essentially highlighting and addressing unique needs of patients. Furthermore, the patient voice can promote involvement of both patient and patient family as active

and respected partners of ratified personalized, effective and efficient care. Infusing the previously galvanized lexicon of medical science and elevated status' with 'lay' language may well serve as a more accessible forum of listening as well. Removing the propriety language of the health-care environment, even removing the listener (practitioner and/or professional) from that environment into a more public and expansive sphere may fertilize the listening/hearing process by displacing medical practitioners from perceived 'higher' standing and posturing away from patient-family voices.

Spoken Word Poetry is classically outlined as a supportive, non-judgmental community of both listeners and performers. As Maisha Fisher (2007) defines, the art is built upon an elemental concept of sharing; older members and performers of the craft ('Soldiers') involve and mentor new and emerging voices and artists, encouraging those new poets in an out-of-the-classroom literacy and learning model. In summary, Fisher identifies three 'types' or identifying features of soldiering within the Spoken Word community. Spoken Word Soldiers are:

- 1. Activists and advocates of all things literary
- 2. Historians of the art/act of Spoken Word, and performed poetry
- 3. Practicing poets or crafts-persons

Fishers' work is rooted in the elemental notion of community within the Spoken Word microcosm, with that community flourishing around a central construct of such domestic environments as classrooms; "home and school literacies as a continuum rather than a set of binaries... [of] growing language and ethnic diversity in our classrooms as well as the pervasive disparities in academic achievement in American public schools" (142).

I submit that relevant story telling is an access point through which to undermine perception that patients are passive and dumbed in the presence of the physician and/or practitioner. Furthermore, works of Spoken Word Poetry can instigate dynamic changes within the oppressed and/or voiceless, simultaneously allowing more heightened understanding of their broad experiences and improving the medical treatment landscape for future consumers and their families. This thesis will interrogate plausible benefits that Spoken Word, as a condensed modality of education, can initiate into the medical field, for instance, diluting the stronghold enculturated power dynamics have within its structure.

It requires immediate acknowledgment that this thesis is neither determined nor designed as a singularly personal/personalized catharsis or therapeutic platform, despite my own acute care/health experience. Though the idea for this project is inarguably informed and inspired by my own illness reality, the project itself is not an elaborate exorcism of personal agendas or scope. As discussed by Brian Lobel in his thesis "Playing the Cancer Card: Illness, Performance and Spectatorship" (2012), there are two categories of illness-experience writing or performance:

- Inspirational stories with a "bereavement trajectory," meant to move the listener with sentimentality as an artistic ambition
- 2. Celebration stories which relate the successful completion of treatment, like Lance Armstrong's *It's Not About the Bike* which recounted Armstrong's "triumph over mortality" (194) and aimed to educate the audience regarding an illness "with language about breaking taboos and silence" (195)

However, my thesis project is not a survivor narrative, having instead a trajectory which intends to blend both the above categories by utilizing Experience, Entertainment and Education (or what I have come to call "TEPP", the Three Es of Potent Performance). In true 'writerly' tradition, I haven written of things I know and have empathy towards, but not solely for my own cathartic release. My poems are of my Otherness as a Cancer patient, intended as a vehicle for those who are unable to present, defend, or tell their own tale(s). My gift is my ability to string words in a captivating and artistic fashion and having an unusual ease in front of an audience gives me increased reason to pursue Spoken Word Poetry as both an art form and a declaration. Although my personal, 'small' story, would to-date or *thus far* be labeled a "survivorship story" (194) by Lobel, this thesis is meant to validate other Cancer patients and their care-givers. Overall, this work will truly be what I consider a success if it can help *Others* to share their *own* healthcare experience with even more *Others*.

Change is possible and change is good—there are no reasons to believe or feel that our medical practice(s) cannot improve in the years to come. By pooling together multiple research styles and perspectives, our current model(s) of health care can evolve into an ever more positive and effective industry than at present. Lastly, as I have emphatically stated, this is not a therapeutic exercise for me, though logically and in all honesty and likelihood, it will facilitate an element of personal release and long-term healing.

BC/AD

before cancer/after diagnosis

by

Kimberly Darcy Anne Taylor

for Del

on
long nights
spiders drag me
toward Mara Lake's rails
where shadow-rich
shacks stand wilted
and aching for

some careless, savage match

into that canyon ghost town over daisied fields and rivers when train tracks smelled of dust breezes smeared our footprints

haunted by chanting children who while the haggard sun sets importantly grass whisped young webs of Rockwell images

en whose kites dance like flies impossible to forget days young ankles and seed-filled images ravel around my heart

I glimpse your twilight skin sweat tempted dark bangs eyes spooned with moonbeams

we walk like this near midnight together again like dragonflies darting thru a sallow stretch of sky, two shimmers of crystal blue

heedless of cancered breasts

and chemo'd hair

Chapter One

secret keepers

but we were only confused and turned our backs and now we are trapped inside our songlessness

"Story Keeper," Wendy Rose

but we were only confused: arrested by an altar draped in pink flags from foremothers, souls divided by logic and half-masted rage; strangely apart we hushed inside, outside

and turned our backs, hid behind the blush in our purses took other women at face value rather than challenge the eye in the mirror which hunted sacrificial sisters among us

and now we are trapped by a shared disease, a bladed ugly sheath, and our young daughters bear the curse of their future with naive minds, breasts perked; stand transfixed together

inside our songlessness where, like spoiled Goddesses we cower, knowing that for every one of us a twin less fortunate will crumple in battle, an innocent statue dissolving in rain

the test

goes beyond insomnia far into anxiety, seaweed in a flash storm waves swamp Self's shore frantic, forlorn

mocks like deep regret crashes headstrong with rage thick as ice-floes loud as midnight fog horns disastrous, damned

offends the future draws family in like tidal foam faces white and windless shaken clean as weathered shells hollow, homely

erodes logical intention sinks harmony in protected bays cold and crystalline simple syllables (*ma-lig-nan-cy*) steal sight, cut breath

blunt force call

Three days before Christmas, 8:10 in the morning, and suddenly my entire world dangles as precariously as one of the little azure balls, sugar-thin, which tempt our ginger cat from branches of the Christmas tree in the corner, its attractive frosting no protection against a short fall onto hardwood.

The tree winks like captured stars, tinsel aglow with ice-blue lights and coloured baubles collected over decades of friendships, loves, family celebrations and amalgamated into a curious hoard which I uncrate each winter, dust off to decorate the traditionally Holiest of holidays.

The phone seems innocent enough, now cradled again in its holster, while moments ago it rested warm against my ear as cold words hunted down the line from a clinic in a neighbouring city, arrested me with a series of syllables that boiled down to one label: Cancer.

I'm transfixed by a solitary leaf clinging unseasonably to the ornamental plum tree outside our living room window—suddenly all I can do is focus on it through frosty glass, uniquely haunting in its loneliness, obliquely fragile while simultaneously Herculean.

Breast Cancer. I don't move from the phone I've just put down as gently as a fevered child, for I know I can't. I must pick it back up in a moment and share my news with my parents, ransack their quiet morning, their peaceful retirement with the horrible news of my *Invasion*, aggressive and deadly.

* * * *

Nothing I have ever done is harder than phoning my parents although I have no real knowledge what the next year will bring to my ignorant self and household -- I've never said the word 'mastectomy' before now have no idea of the process, the pain, the scar, I

don't foresee the infection, hot as steam and so painful I won't sleep for two nights and three days until I visit my surgeon whom I'm convinced thinks me weak when I insist on an appointment because I'm brittle from sleeplessness and pulsing with over-sensitivity, I

have no inkling of the shock I'll experience after stepping out of a too-hot shower to see tubes dangling from me like plastic tentacles, my amputation so angry and vibrant it'll trap me to drip dry against the mirror as I whisper calls for help into our empty, foreign home, I

don't know I'll lose every single hair in my first round of chemo experience the full scope of side effects: mouth sores, sandy eyes, blistered skin, yeast infections, unrelenting fatigue, nor can I possibly perceive the anger which will splinter my soul, distance me from myself to the point of despair, I

cannot imagine how strangely I'll be viewed by my husband, how ashamed I'll be of my behaviour after each AC treatment because my body is too sensitive and the dosage too high though after it's dropped and dropped again I still suffer, I

can't know yet that I'll visit counselors and doctors weekly, swallow hundreds of anti-anxiety pills and spend a hundred and fifty every treatment for the anti-nausea's; *gems* I'll call them as their value escalates exponentially with my need and their effectiveness. I

am ignorant of what *tired* really is until half way through when I won't be able to settle longer than two hours because my bladder's bursting with urine so toxic I've got to plug my nose every time I flush, and I

don't fathom how my husband will be stifled by his inability to *fix*, something he easily does every day as a carpenter with hammer, saws, concrete and nails, but against this disease can't build a fortress, can only watch from afar as I splinter in battle.

* * * *

In fact, my husband left for work an hour ago, snuck out of our warm bed, made himself a thermos of coffee, and turned on Christmas tree lights to greet me. I've awakened to this rancid phone call, stare now at the coved ceiling on which holiday colours are suddenly carnival and drunken, sickly brilliant.

The naked plum tree outside stands immediately appropriate, contrasted by its spectre-cousin kaleidoscoping in my nearest corner, its remaining single leaf, once rich and red now shudders like a grey skeleton under a coat of sparkling coastal-frost which makes me feel so very small.

A new doorway opens somewhere in my frontal lobe, an iced phantom creeps across my scalp, slithers down my spine, births a fine tremor that I know will linger there for a long, long time. It's the terror of a disease I don't want, would do anything to mutate away.

Panic freezes my core and I start to shake uncontrollably, there seems no silence as my body screams with a fear I'm a stranger to. The room pales to white, fractures at a nightmarish angle as I grasp for something, *anything* solid and familiar; only then do I finally make a small, strangled sound.

But I don't sag in my chair under the weight of diagnosis, instead I become as stiff as the plum tree outside, as posed as the festive tree inside though lacking in its volumes of colour. Yes, I thirst as if suddenly deserted, my reservoir too empty for tears, my mind too shocked to calculate the enormity of changes I face.

But a bitter confusion assaults me with blunt intensity: I don't *feel* seriously ill, nor has my body ever made restrictions about what I can and can't do (that's my mind)
I'm young, healthy, fit; how could I possibly be so dangerously mortal, as fragile as this phone call has just declared?

My breath is rasped, as shallow and harsh in lungs as when I rode my bike to work through lower, wetter weather belts on Interurban Lane, past flooded fields where swans collected and swam like white dreams through morning's frigid light, mist falling from low clouds and rising from still water to meet.

I rode hard just recently, pushed my body to its maximum threshold and, with speed my delight, aimed for a higher personal fitness with singular strength and youthful focus that now feel as far away as Heaven, as unreal as the angels I imagined in the bodies of those white birds floating on that silent, winter slough.

* * * *

The phone is cold against my palm as I dial my parents three days before Christmas from a hollow household four hundred miles away, where for the next several, stretched-out months, my perception of God will be tried in fits of silence, pain, shock.

I put the receiver to my stunned ear and whisper to my father when he answers,

"Sit down, Daddy. Sit down."

ocean, earth, and limbo

twenty-three foot missile cloaking a thousand teeth, skin glistens, dorsal cuts like a scimitar, crescents curling tight to carve hollow caves in waves, stir an eddy to sucking-speed, dig a grave out of water swifter than serpents fast as thought under a blind silver moon

mystical pine and cedar shield Ursus from sight: it snuffles, shrugs its musky way across clearings through trees coming closer, circles (felt as heat on neck hair rising on arms a malicious wind) circles in shrinking radii, closer closer, camouflage of leaves in fall, grizzly hunkers hungry on my trail

and me, caught with a foot in each sphere

beginning in waves

vast beach seaweed tossed sand spread in rough blanket

: no warning:

tsunami plows forward sand becomes water becomes concrete, demolitions a swath of nothingness through landscape of huts, streets, schools

flattens me clean

scraps dance and churn amidst carcasses of other talents I dreamt of nurturing: sad bits of bright rags bob and collide in water rancid with early death

recession is calamatously quiet

I hear the Earth weeping somewhere behind me

New Year's Eve

Well, let's see if I can do this in 300 words or less:

I'm in a bad space, exhausted and unable to sleep. I can't stand listening to [my husband] snore fitfully beside me, so came down to the couch where I'll listen to the dog snore instead. Dr. Olivotto called me tonight, telling me he wanted me to have surgery *last* week, but that I'm healthy enough for chemo; telling me it's far too late for me to hope alternative medicines could make a difference. He's says I only have 6 months left. Apparently the possibility of "early stages" was dashed long ago. Guess I missed the memo.

I know thousands of women survive this, but I'm having a hard time adjusting, focusing. I could really use some physical support, but [my husband]'s totally unavailable, unreachable, unbearable. I don't know which is harder to stomach: my diagnosis, or this sudden, intense loneliness. I told Dr. Olivotto he had to tell me everything now, because the next time I see his name on my phone, I won't be able to pick it up. I can't take any more of his news.

So, I'll know my surgery date first thing Tuesday, and then things will really start going fast. According to Dr. Olivotto, the speed with which he and Dr. Carr are dealing with me should indicate the severity of my case. Oh Shit.

I'm sick of all this already, and would <u>love</u> to just run. It's weird. It's an instinctive reaction that I literally can't control or even touch. But it's not that I want to jump into a really fast car and race away. It's not that I want to hop on my favourite bike and shoot out of my *here*. It's this bizarre body-thing, and it's everything I can do to NOT just turn and RUN the other way. And as a cyclist, I freaking *hate* running.

Talk about not feeling like myself!

But no matter where I go, my body will accompany me. I'm out of luck—there's no getting out of this one. I'll have to figure out a strategy and ready myself for the biggest war of my life.

D

Frances

eight and clumsy, brave well beyond my means deep-end beckoned, challenge of epic size, a dare too great

must have thrashed all the way to the rich, blue bottom pale sky surface glittered above rippley rows of 1-inch azure tiles

heavy with quiet (like being buried I think) eyes burned by chlorine, lungs chugged full of water and sleepy

no recollection of the in-between-ness or surrendering to the bright blue tones under my wallowing wrists limp without air, and

Frances was there, her usually silver-blonde hair plastered flat against her small skull, mascara thick as mink staining her face

spattering little wet ribs she had hauled from the deep end, one of her tan sling-backs trading places with me on the bottom

her eyes were California blue intense with frightened fury her long fingernails mooned scars into my arms before she finally released me on deck thirty-two years later, my friend's mother has come again. She sits on my hospital bedside, quietly strokes my hand with her thumb

strange yellow sun light charges the room—fireflies at noon—silver hair hangs long over movie-star smile, brings back a familiar loving fury

this time, she is not angry at having to jump in after me—she smiles, happy to halt my drowning and pound air into me again

we sit silently, Frances stroking my hand, and I breathe deep as my eight-year old self when answering the power in her hands, her urgently gasping my name

still groggy from anesthetic I am soothed by her presence but have forgotten that Frances has long been gone, taken by her own terrible cancer a half-decade ago

January 19

Hi everyone: Just wanted to thank you all for the prayers in the last few weeks. I've definitely felt them, and even can attest that they, when being performed, appear yellow. I woke from my surgery to a room with yellow, sparkling light, filled with love and peaceful feelings. It may be a bad analogy, but the room sparkled like the inside of a glass of gingerale--kind of gold and bubbly.

I am so thankful for all of your energies and thoughts at a time when I so need and want them. I did not feel alone or afraid after my surgery; just loved. Thank you all.

So far, things are looking pretty good. I have another appointment with the surgeon, and another with the chemo team, and will embark on the next leg of this race very soon. To me, this is another bike-race, though the course is different than any I came across during my competitive days. It is similar however, in that it is mapped out—a course on which I'll 'pedal' my hardest in order to finish. It will be hard, and some moments I know I'll certainly wish to quit because it'll hurt enough to want to, but I've competed in enough races (even won some) in which the middle of the event was the hardest thing I had ever gotten through in my life.

I can do this.

It's all those Taylor and Schultz genes—you know, the staunch, proud English ones, and the stubborn, hard-headed Dutch ones. Thanks to my parents, I'm 100% covered in the attitude department.

Blessings to you all, and hugs of thanks.

~me~

obligations of the nightmare

And the world begins again.

Hurry up please it's time.

It's time and a half
and there's the rub.

"Junkman's Obbligato," Lawrence Ferlinghetti

I: it starts here

landscape awash with the ghosts of two women I wanted to become, two pioneer-sirens whose ill luck tore them from sisterhood, their fame and talents capsized by pirates and blackening spots barbed with fear. They are suddenly close enough to touch. I dream them both hear their lament usher me from my own garland of ruby notes hung cowardly in their footsteps. Too close now, seraphic voices crescendo to declare my elegy a froth-white room filled with sisterly, turbulent disease.

II: Gilda's Wigs

And the world begins again with another laugh, a different skit and change of wardrobe, brighter lipstick, maybe a wig

Hurry up please it's time for more humour, laughter heals: all the world comes together over the best joke Gilda tells

It's time; and a half her soul becomes improv while her ovaries grow grey under pancake rouge and studio lights

and there's the rub she masks bellying darkness with props, seeks a memorable role in her audiences' guffaws

III: Judy in Red

And the world begins again for her in a clear bottle filled with courage, Oz, and a Broadway ticket away from here

Hurry up please it's time she feels flaking away in her hidden heart where laughter curdles and music can't hold its tune

It's time and a half to rehearse lines and lament where no-one can see her twisted fingers or hear her voice crack

and there's the rub again; and again she swallows her problems ounce by ounce while her smile breaks through bitter lips

IV: A Joint Appearance

Monday, 4am:

And the world begins, again
Judy links arms with Gilda and
advances on me, smoky floral prints
sway as they grasp me like
exploded cattails in a freakish
breeze, seeds jigging away
from my shadowed stalk; their
frantic whispers slice my ear
Hurry up! Please! It's time!

Monday, 6am:

It's time, and a halflived life stalks me round my yellow kitchen, dredges the nightmare which hunts my fearless, green life with night blue eclipse, threatens to freeze me like the star of Miss Monroe, kept at a constantly bright but regrettable age and there's the rub

V: Friday, near noon

And my world begins again with memories of lost virginity to a solemn fortieth birthday when no-one dared bring cut flowers

Hurry up! Please! It's time which passes so quickly--I know no precious moment can be gently withheld, slowed, or fully understood

It's time, and a half measure of days fizzles, my hazy mind darkens as these ghosts swing Hell's axe in league with this worst Hell

and there's the rub:
I wanted to experience everything at least once, but that includes
Death and fear of Death, and the shame

of quelling one's inner flame

V: Saturday

And my world begins again after an age of sapphire mist and moonstone blue, a wave of neutrophils sings work-ready as plow horses in spring: "hurry up please it's time!" They chop the icicles stretching down from eaves on my stale mountain cabin. In this landscape too scared for sound, it's time and a half since winter: trees stand rusty and scarred by pine beetles, their near-death trunks like charred sign posts in spring rains. And there's the rub; though clearly marked this pathway doesn't expose the caustic darkness of any secrets my body may still be keeping

cycle one

I was a competitive cyclist, coached into a lifestyle of being the strongest woman I could be by chasing the clock and every cyclist ahead of me
I was a downhill daredevil, courageous, crazy and brave. But right now adrenaline's crashing through me and I'm shaking uncontrollably, and it kind of feels like racing like when I'd carved a corner out of a Canada Cup downhill race, caught my "minute-marker" on a capricious angle passed her conspicuously close and was careening into the finish, teeth clenched, confidence flaring, in complete control

only there's no corner, no confidence, no control

My consciousness feels cracked in two and I'm cartwheeling so hard I can't concentrate clearly—it's confusing considering I feel like I'm going *that* fast, so I've got to clear my head and accept this is not a Canada Cup Downhill Race—this is a chemotherapy unit, and

Here I Am.

Cancer's a concept big as a continent: microscopic cells have crept together and clustered into clumps called tumors I'm convinced I had no clue it was occurring but can't be crippled by corrupt cells I can't see!

So Here I Am. They tell me chemo will collapse my life by killing every cell inside me, but that chemo's my only course of action. I cower against this caustic experience but I've got no choice if I want a cure. These chemicals can kill me as easily as cure me, so all I can do is hope the Creator has cut a new course for me once *this* course this *chemo*, is complete

Here I am: confined to shaking in this crinkly chair in a chemotherapy unit, trying to calm, to cope, by concentrating on my old life, my bike, my conquered challenges but I cringe as Cycle One of my chemo collects inside me. It's creepy how cold I feel, how cautiously I crept into this cavernous white room with clean walls, career nurses and chrome. My teeth chatter and I'm accosted by questions about my mortality

Here I am

Quite frankly I'd give anything not to be here, not HERE even though I don't feel alone: the air here is thick with shadows of countless cancer patients come before me male, female, young, old. They're all crammed in here like mist, and if I crank my ears and listen closely I can hear a quiet whisper of support, like the crowd at a Canada Cup race, and they're saying if I could do that kind of cycling, then I can do this kind of cycling too

I cave into myself before I can possibly conceive they may be correct. I may be cowering now, but I'm going to convince myself that I CAN DO THIS. I'm a competitive cyclist: I can come through eight cycles of chemo and confront this cancer with courage. I know I can and must, so start imagining confining and crushing every cancerous cell my body may ever contain: cancer will be my next race, my new minute marker

Here I am

cycling my way to a cure with a host of chemicals inside my veins. It's crazy but I can suddenly conceive of a new course curling out around me and I find an odd comfort in a childhood cliché as Cycle One of my chemo concludes:

after a fall, a cyclist needs to climb right back on their bike

So now, here I am, courage re-charged, and changed to my core. I am here but Cancer isn't just my race—it's everyone's—and together we can challenge our chances and come through each corner and finish line re-charged and confident. We can stand together, we can chase, crush, and conquer Cancer.

We can.

Here I am, and I believe

winter bird

- the whole fan-damily

husband disarmed in shock stands helpless, knighthood and shield lost, his white horses lamed by disease

> brothers cry openly, hide their own mortal fears like lizards sunning on hot asphalt down south

sisters

turn to laughter
make me buffalo wigs
to offer me warmth on days when
I'm alone

parents understand their daughter can die before them, unprotected despite love and want

uncles

fear the worst, talk of death like He's right there in the room already, standing, waiting

> aunties send cards and call monthly, discuss treatment like it's a new recipe for dinner

grandmas quickly recall a name, a face, my eyes as memories roll freely once again

> and me caught between cold and crazy, a songbird almost silenced, unable to migrate

February 9

I lost all my hair, pubic hair first, in the shower. It started to come out, and it clogged the drain so I had to keep scooping it out with my hand.

There shouldn't have been that much really, because [my husband] tried to help me cut all my 'long' hair off on January 22—getting ready for my first chemo later that day. He used the #4, and it was his reality-maker to have my hair falling onto the floor in clumps. He couldn't do it, got 1/3 my head done before he left me alone in front of the mirror, to finish it myself. We both started to look at me differently that day.

That was two weeks ago, so tonight in the shower, I razed my scalp with a Bic. Now I'm as smooth as a Tibetan Monk, but a long way from Sinead O'Connor because my eyebrows fell out too. There's no camouflaging I'm sick now: I'm bald everywhere.

Can't express how my scalp feels—it's a constant, seriously-cold chill running across it—and I know this is the temperature of death, of dying cells, of my treatment and my future treatments. One of the chemo drugs feels like this when they inject it.

They set up my IV needle and port, and then the nurse goes to the fridge and brings out this horse syringe filled with red, clear liquid. After she checks the label several times, she inserts the needle into my port and starts pushing the liquid into me, slowly, slowly. She gets really intense ("look right at me, please"), and watches me very closely. When someone looks at you that intently, it can't be good.

It's eerie. Even though they wrap me in heated blankets and cover my arm with a heating pad first, I can feel the chemical move into me. The first place I notice it is my lungs, which get all icy. I've never had cold lungs like that—they are on the inside so are always warm, no matter the temperature of the air I breathe.

But this red stuff makes them immediately cold. Bizarre.

Then it's my blood I feel—the chemical progressing through my system like a cool shadow. It scares me to have that coldness seeping through me *from the inside*. It makes me scared in a way I've never been scared before. It feels like my blood and all my cells are scared. Good thing they wrap me in heated blankets or I'd bolt, despite the Ativan they give me first.

And I have three more treatments of that chemical to go. I wonder if I will be cold the whole four months of it. Judging from how I feel today without my hair, I think the answer might be "yes."

I have to sleep—exhaustion will be my acute enemy by Wednesday. And I have my next chemo sooner than I think I'm ready for.

cutting thunder out of tides

Is the total black, being spoken from the earth's inside.

There are many kinds of open how a diamond comes into a knot of flame "Coal," Audre Lorde

Is the total-black being spoken
her universe of blood and bones, looking
on her moon-round face mirrored each
moment as her ominous thunder sighs
softer, softer, tremors too shallow to
register, and her rained body hopelessly
reduces to mercury dribbling hanging

from the earth's inside,
off cave walls propped inside hours
rough as gooseflesh, beside energy dry
as coarse salt, barren as whispers. She
replays her formerly rosy life, skirt short
enough to call bees to her petunia
mouth, eyes flushed open.

There are many kinds of open:
part, wide, a crack—but none prepared her
for such brutality or raging nature where
she's currently captured, a startled bat in
a horned owl's claw shocked by a predator
of phantasmal presence whose bleak strength
spreads like coal powder on wind masking

how a diamond comes into a knot of flame the sun to its rise, smooth as the turning Earth and Her surging galaxy; she wanes without eyebrows to tweeze, blemishes to pick, hair to cut: stripped of diurnal orbits, her arc darkens for without stars to graft her, she spins unbalanced tideless.

April 9

T---:

Thanks for the genuine email. Very sweet of you to inquire after me. Your questions are no problem; I'll answer as best I can. I have found that most people, myself included, are completely ignorant about the full spectrum of chemotherapy. They don't know the side effects, the process, the duration.

The bottom line is that chemo kills ALL your cells, so during treatment, a patient has no immune system whatsoever.

Chemo works like this, there's usually a three week turn-around: get chemo Wednesday, have it again in three weeks, and repeat as prescribed. Your blood gets checked at the hospital the day before your scheduled treatment. Only after testing all your levels (from Ferritin to Nutrafils) and ensuring you are healthy enough, can they administer your treatment the next day. If your blood levels are too low, you have to wait a week. That's called a "delay." If you get a delay, you have to get your blood retested again in 7 days. If you still haven't recovered, they'll reduce your dosage, or maybe you could afford this drug called Neupogen which boosts your blood counts (but I've heard it costs the patient \$500/shot, and you need 5-7 shots per treatment).

It's better not to have your dosage reduced because they can only quote you cure-statistics based on a full course of treatment, with at least 75% dosages each time. They can't guarantee chemo will work at all below 75%.

Unfortunately, I have found chemo quite rough. I'm one of the rare ones to get <u>all</u> the side effects. Lucky me. I started chemo in late January, but had two delays, so have only just gotten my third round. I'm a few weeks behind schedule. My friends and family are being supportive and inspiring, but it must be tough for them to watch me go through this, certainly when they can't do anything to make me better. I think it's not only the patient who suffers.

Just last week, however, my specialist reduced my dosage to 80%. Seems my body can't take a full dose, and the oncologist told me I was "alarmingly toxic." Yikes! I had chemo last Wednesday and this week I show signs of 'recovery', as opposed to zero % recovery for three weeks after a 100% dose.

The 80% dose is WAY better. I'm able to go out (not often), but have to wear gloves and disinfect every part of myself when I get home. I can't touch things that others have touched (shopping carts, interact machines, door knobs, money). I'm awfully fragile right now—so I'd rather stay in, boring as it may get.

I ordered a huge box of essential oils last month, so am using a lot of oils to combat things like moods (I make Medusa look like a sweetheart), appetite dilemmas, nausea,

and insomnia. I can't put them on my skin, so am using them airborne in a 'sonic nebulizer.' Sometimes it works, sometimes it doesn't.

You're brave to ask about dying. I don't think I'll die, but I realize it's more that I don't want to. Whatever—it boils down to the same stubbornness, but I can't let myself think about it too much. I'm too weak to pull myself out of any holes, let alone the abyss of wondering about my mortality.

You are also right that I feel very lonely, despite people calling and writing. I miss the interaction I had in my former life--from feeling like a wife, from school to playing squash, from going for coffee to biking with friends. I've had to become reclusive, since I'm an infection risk. I didn't have the option to wait the regular six to seven weeks between surgery and chemo. I had two surgeries, then just two weeks before my first chemo. I started my chemo the same day I finished meds for a massive, post-operative infection. Chemo was started when my body was super weak; not optimal, but there was no option.

Not everyone is as understanding or open as you, T---. One couple we've been friends with dropped our friendship. Sad, but I can't blame them; I'd like to turn away and ignore this cancer too. I'd be happy to run away, but can't. Another couple asked my husband if they could have my new bike and my racing gear, since I "was dying anyway." I wonder if I'll lose other friends, but I guess I won't know until I haven't seen them in a very long time.

And so I thank you for asking me these questions, and for contacting me. Talking/writing about it keeps me grounded and prevents me from getting freaked right-the-hell out. Writing is my saving grace right now. I wonder what patients do when they have no hobbies? It's easy to get swamped by the drama of it all, and what keeps me real is reminding myself over and over that this is temporary, that others have survived, and frankly, that I have too many things to do yet with my life.

By keeping myself realistic, and by reviewing the logical process that is my treatment, I find a calmness and a clear path to follow. Wouldn't you know, the path is only one step long, though.

But really, all anyone can take is one step at a time.

D

icing

apparently there's never been another student with cancer, another loan recipient forced to fight for life they're having none of it, and need proof of income, proof of illness, proof of medical expenses

so forms, endless papers I must provide; do the frightening, dangerous trek to a germ-covered store for a public fax so they can have it all fast, as my wallet thins terminally and my cupboards gape bare

I bloat with nausea and eat anger borne of more than chemicals meant to kill errant cells, call after call fax after fax and still they don't have enough proof, bank statements or doctors' reports: it's their bottom line

into the phone I sob, face stuck to a receiver caked in snot and the tears of my thousandth plea can't you understand, I'm SICK; have you any idea the cost I pay to leap through your fucking hoops?

chemo isn't a valid enough reason to defer my loan a measly few months, so at two-point-five above prime, they invade my security though I'm freezing in June (but that's not their problem, after all

I signed their contract, took money for schooling to solidify my watery potential) I've learned much in these years, but know most there is no good will, no port in this typhoon of principles

Chapter Two

Meditation I

Cool smell: root vegetables left cellared squandered to worms. Close your eyes against city-thought, open your body to scents of rich highland

shaggy mountains

Audience, critic, artist, model-be awed by the miracle of daybreak allow breath to snare in your throat, listen as peaks whisper of rocks and rivers

alpine air

breathe clearly, in *let brightness fill your corners*

breathe strong, out

let dust and cobwebs leave you

Reverence is a *red* splash behind peaks as sun breaks behind their shield breathe in their

fire, warm your feet

exhale dust

Meng-mein is *orange*, glowing atop granite slopes cheerful as embers

breathe in energy

like Crocosmia to your belly

exhale fog

Rising sun floods *yellow*, fills dark gullies chases night from sleeping flowers

breathe in, tuck

a rock-rose in your naval

exhale sand

Meadows glow vibrant *green*, young grasses bud, spring to attention all around

breathe in, clasp

this fern to your heart

exhale cobwebs

Above mountains, sky shines *blue*; breezes smell of over-night, alpine frost

breathe in, place

Gentiana jewels at your throat exhale rust

Higher yet, air is *purple*--a soft haze calms a wakening earth below breathe in, drape

Lobelia vines on your forehead

exhale shadow

Clouds form in *white*, skate on currents unseen sweep into shapes unimaginable breathe in, picture snowdrops arcing over your hair *exhale dust*

hear Nature's spectrum hum in your ears as cleansing powers of this rainbow travel through you like stones' pulse endless grasslands

allow stillness to spread over you like a warmed blanket. Be calmed. Be a wilding garden.

ferned mountain base

breathe clearly, in *feel brightness fill your corners*

breathe strong, out

feel dust and cobwebs leave your thoughts

breathe deeply, naturally feel balanced with Harmony

Pause. Rest your lungs and know the gift of Peace

breathe strong

deep

and know.

smooth

```
never could have
      imagined
my head
      resembling
billiard balls
       new leaves
rose petals
      porcelain
new paper
      marble sculptures
baby's toes
      gull's bodies
patent leather shoes
      rocks from China Beach
i wonder
       when
(maybe curly
      what colour
how soft?)
```

it'll grow back

a balance in imbalance

quick as toast we're friends brought together to witness science, detail our pains and loss of dignities like kids trading bagged lunches

> minds stutter with effort as memory falls under siege, replaced by orange urine, loose stools veins playing more hide than seek

absurd how like porcelain we've become, so shiny and pubescent our hairless legs, our underarms smooth as eyelids!

downplaying brevity, living to change regrets, we weep and discuss Death & Life with callous honesty because our fantasies failed us

newly magic, we empathize without speech feel without eye contact, know without hearing the whole time trying to calm our instincts which ricochet between Run and Stand

come again

words are foreign particles thieved from a past life

fictions have fallen hamstrung mid-dance

muses have succumbed bludgeoned deep blue

angelic faces grimace tongues hacked out

dresses shredded sandals caked with blood

there are no footprints left to follow

when poison is poison

no choice: nurses assigned my seat today and I'm next to the double-wide doors that lead to the private room which houses the crash cart

guess that's just how they deal with how my veins nearly exploded during my last treatment, guess it really was as bad as it felt

I have a view of every one from here but no one's looking at me on account of our general fear of those two doors opening fast

a new lady comes in and they seat her near the entrance (ooh, a first-timer) so she and I are like gargoyles perched on opposite corners of Hell

she's talkative, looking vivacious and kind of relaxed but that veneer's too damned thin for the likes of us we know how much she's shitting bricks inside

out of respect we kind of ignore her to let her keep pretending, but our radar picks up that needles go in to her no problem, that her veins are plump and still naïve

and I feel it before even the nurses notice, my skin gets terrified, feels like razor blades so I look around to see her suddenly super red, eyes rolling back

and then it's the same scene as my last treatment, only from my gargoyle-spot not the patient-spot: four nurses efficient as herding dogs, float really fast to her side

pulling tubes
reclining chair
grabbing heated flannels
silencing alarms
doing all they can to not rush-open those double doors

as two Oncologists with soft-soled shoes run in join the huddle for however long it takes until she's the right colour again

I'm the only ghoul watching as all the rest of us feign sleep, or turn away or completely off, or become too thin to respond so only I see the doctors' lips mouthing "it's over"

and then she's sitting upright terrified, digesting news that she's allergic or toxic or something that means she can't even have her chemotherapy, that even poison won't work

I see her mouth moving over and over and around bewildered words "what now?" as she struggles to accept that all her chances just died, and I wilt

for her, with her, about her, sitting in my recliner cold as death from poisons trickling safely, willingly into me, mouth dry, eyes wet with some bizarre, unnameable wave of guilt

three for comfort

it's just temporary

toxicity is a constant mood: thick as smog over a spreading city, deadly as smoke from wood frame buildings going up like thin torches, flames rich with hunger, red as blood under a hospital microscope every third week

it's just temporary

there's nothing inside but ash: the lunatic I've become threatens more than cancer and I forget positive, loving, loved while medicine poisons beyond the cells it's injected to destroy and "I" dies rapidly in that reign

it's just temporary

the brackish woman I've become: eyes dart like a savage's, furrows like cement levies between them, rot spews from a mouth I can't control (don't even know), sharpened hatred hangs me out of sight from my Self

it's just temporary

this risks permanent bitterness: but I don't want to become an old lady, white hair pulled back, smile stretched onto basset-hound face rouge slathered clown-like on catatonic cheeks, grotesque lipstick smeared outside the lines

it's just temporary

three words: though hollow and minute in my temple, bare of gold, candles, and altar my church shrinks without congregation of spirit, grows silent as stone under my shrieking heart, soul flailing in a stained faith

such small things

```
somehow it's reasonable to define beauty differently evaluate my Self by stranger things my vocabulary and talents, the quantity and quality of laughter, the goodness of others, the breeze on my skin, the flowers I can stare at for hours
```

despite modification by amputation and a few dozen steroid-pounds I feel feminine and more able to love myself I also crave the future

this ugly treatment is my best and only shot so everything's bearable down to the last damned humiliating side-effect, bearable enough that I still dream, declare my feelings, smile from my belly out

I'm weaned off success my thought it'd render me happy and healthy fades as I realize I lived like I'd been branded, had forgotten how to look down at the path at my feet

my world has shrunk with blazed precision: I live in days, not weeks months, or anything so grand as a year. I've narrowed it down to time spent doing better things

in near-deathness I've found permission
to spend time on sleep to uncover clarity
to focus on immediacy
and live day-to-day, to accept and
celebrate the value of small things

now that's a much healthier time-line

June's encounter

```
a magnet made me
       reach out
       hold her
       cry along
in the hospital corridor
in front of the blood lab
her right arm red
       swollen like bee stings
by the pick-line they'd
installed to irrigate her
with a raft of
chemotherapy drugs
for the next
       several months
in an attempt to kill the
Stage III colon cancer
she was diagnosed with
       five weeks earlier
```

her husband wept behind her his face poppy-orange under fluorescents, his eyes pleading for this all to be a hideous dream from which he would awake find her safe, warmly nestled to his chest in sleep under the flower-print comforter on their bed

I made her breathe deep told her it'd be over sooner than you think tried to present some Hope knowing the whole time my breath would remain stalled in my own throat, that I'd worry for her outcome (she's a year younger and I'm too young to go through this) knowing too that

for many months I'd often take time to pray for her a stranger in all ways but disease

they're piling up

in the mailbox, those used ribbons from my parents' friend I've met a half-dozen times: Rick runs, runs marathons wherever they turn up, like an addict he registers then trains like a phantom on frigid Interior mornings, muscles thinning to striated springs which launch him off start lines like a middle-aged comet twisted pink ribbon pinned to his number plate over his heart, ink barely visible

for Darcy, because we can!

Rick's running to share with me breezes across skin, hooting crowds pavement passing like river beneath his sweating legs. Rick's running because it's all he can give my parents for their youngest child—throughout his marathons he pictures me healthy, pounds that perfect vision into solid earth at his feet where it can smell soil and drunkenly take root while he sends me psychic images of the wild, winding course stretching out ahead

playing poker

Can't ask you to gently rub my back if it lasts longer than mere moments

I gamble it being your standard six point five minutes of dry intimacy

when my docs all say *don't!* and my thin skin agrees by tearing

instantly

with no bluffs or red hearts to win I tense to fend off this risky bet

my silent face blank, two pillows propped between knees and under my arm

waiting for solo snores while I pray my cards will look better in daylight

(I think it's) June 28

I'm beginning to feel better today. My anti-nauseas are gone for this round, and I only lost seven pounds this time. I know by next week the steroids they have to give me will have me bloating like a carton of sour milk, but I'm not bloated today, so it's a good day.

My eyes feel like 40 grit sandpaper in the desert sun. And I now have the wonderful distinction of having a staph infection all over me. It's worst on my scalp, and I've never been or felt uglier in my life. Besides the fact that I can't see all that well these days, I don't *want* to see myself in the mirror. The room turns at a nauseating angle when I can see it reflected behind me anyway. Circuses and fun-houses all the way.

At least this round I didn't barf. Christ, Lord, and God above, last chemo was nuts because I ralphed up this toxic goo that made my eyes literally burn as I leaned into the toilet bowl. What I yakked up was so foul and so *hot* that the toilet was a uranium mine.

The worst thing this time around is that my skin hurts like mad; every time I move too fast or there's a big noise outside, my skin suddenly feels scalded. Everywhere: my shoulders, my ass, the soles of my feet, the back of my neck. My poor scalp. Oh God, my scalp. They didn't mention any side effects like this in the literature. I wonder if I'm the only one.

It hurts to have blankets on me, but I'm too cold without. It's bloody June and I've got the fireplace raging while I shiver under a down duvet on the couch right beside the dang fireplace. I wish someone would come and stoke the thing for me—two feet feels too far to go today... Even the sensation of daylight hurts my flesh like a burn. I've stuffed my ear plugs in as far as they'll go because I can't stand how much my skin hurts from the noise of the traffic out front, or of the logs crackling only feet away. *Noise hurts*. Just another swell day on Fourth Street...

Silence. Silence. Please.

If I died today I'd feel totally ripped off. There are too many things still to do. I haven't donned a white suit and dealt with bees; stuck my hand into the throbbing, buzzing mass of them and partook of their honey. I haven't seen one stitch of the Nahanni River. I've never seen a wild fox, mountain sheep, rattle snake, or grizzly. I've never been to Ayers Rock or listened to the sounds of fruit bats as they swarm over the jungle river beds. I haven't seen a professional baseball game. I don't know what Nasturtiums taste like in a salad, or how to make Yorkshire pudding. Who knows what my friends will look like when they're old, how my nieces will look at their weddings?

I'm not *clean* enough to die. There are things still to sweep up, deal with. There are people out there who don't know how I feel about my relationship with them. There are things left undone. So many things I haven't *conflicted Constructed constituted* Shit. What is that word? It's when you are combative and you bring something up with

someone you have an issue with *contracted compressed convinced* Damn brain. What is that word? It's when you do something you have been thinking of doing for a long time. To fix some situation that hasn't gone the way that makes you feel good, right, settled about it. Undone. Unfinished. Unsatisfied. *Constituted* I haven't *combatted*—that's not it—*combusted* give me a fricken break and think of the damned right word!!!

And some specialists think that "chemo-brain" doesn't exist, that it's something patients *make up*. Sure, like I'd have energy to make ANYthing up right now. It's one of the worst side effects, to not be able to think, not be able to read a damn thing because I can't follow a simple sentence—can't remember what the subject is by the time I get to the verb. Thank goodness I can type so fast, and can get the thoughts down almost as quickly as they come.

I do wonder though, if this will make any sense later on. I worry that all my "salvation-time" spent at the keyboard will turn into useless paper, crumpled in the bottom of the waste basket. The big fear is that my sentences are actually incomplete, make no sense, they'll never roll together in a cohesive paragraph... And I can't trust myself to know.

Watching TV is really no better than trying to read because I can't recall what happened before the commercial break. Being frustrated doesn't help, but Fuck! I feel like hell, look even worse, and can't think myself from the living room to the bathroom without wondering what the hell I'm up for.

CONFRONTED. I finally remembered the word! I haven't *confronted* some of the people who have wronged me. I just sat there and let them run me over like I was worthless, but I am not worthless: I am as valuable as gold or diamonds or *oxygen*.

Damned if I'm going to die today and let myself feel this unfinished, this cheated out of my Self and my Being by other people who put themselves higher than me for the simple fact that I have been non-combative because I am so god-damned polite and soft spoken. It was drilled into me that you can't be *rude* to others or hurt their feelings. God knows that would be *wrong*, *bad*.

My upbringing chaffs me raw some days. *Polite*. Damned waste of MY time in most circumstances, to tell the truth. I'm combative with ME, because I can control that fight. I can win (or lose) *that* fight. Why have I not honoured my Self and stood up against those situations where I've been harpooned, maligned, under- and de-valued, *pissed on* for crying out loud?

I haven't cleaned my slate. I need to address some of the personal injustices I have both been victim and orchestrator of. I need to be cleaner. If I can get through this chemo, this cancer, this lousy fucking test, then I should be able to extend the time and energy to clean the hell up. Deal with all those things that, right this moment, press against my mind in the form of REGRETS. Life is too short to be stuck on this damned couch and thinking of all the things I *should have done*. Piss on that. So what if I feel like hell. So

what if I naturally figure that death is too close for comfort. Today is not my day to go, no matter how big a pile of shit I feel I am, or feel I am in.

The real issue here is that *I'm not fucking done yet*. My 40th birthday is just around the corner, and I still have fears and people and situations and *all sorts of crap* yet to confront.

rowing in July

it's the first row boat I've sat in and it belonged to her father, long dead long missed. She honours him now by escaping onto a familiar sea with someone who can't row herself

this skiff she once passengered carves out a silent wake while I marvel at yellow ribbons of light taking leave of twilight and settling onto subtle waves around us

Margaret stretches long as she rows us out to Newcastle Island, around the left where magic stumps of sandstone lurch out of midnight seas like ghouls, wonderful and strong

she removes her clothing, slips into crisp salt water, declaring it warm and delightful, then tows the boat round the bay to stir phosphorescence with her small feet

at first, my eyes think it bubbles pale as her skin, created by movements of her body—until night matures and the sea becomes a flat, dark slate upon which glitter marks our route

we are suddenly faeries in an ancient ancestral land, restrictions forgone and diluted by a million moonrises on a familiar shore where nighthawks and dew-catchers flit after wave upon wave of night

I drape my fingers in to tickle up my own glowing cloud just as a green outlined fish swims under our vessel very close to Margaret's sparkling legs delighted, I shiver almost violently I want to stay in this boat on this water with her, floating safely away from reality Margaret says she understands, but that she'll take me out again sometime when I am feeling better

Chapter Three

Meditation II: learning to float

The worst worry can be a prayer boat.
—Connie O'Brien

Damp with fog, heavy blanket wraps her shoulders, shields from an imagined wind. Closed eyes study whole-grey expanse as sunless horizon looses chill onto wise rocks under foot.

She concentrates, waits. First light shimmies emblazons bright pinpoint onto psychic grey waves. Inhaling crimson of yawning daybreak, her body unfurls as Hope flushes cheek and sky.

Exhalation weakens her newest shadows chases curling light across wave tips bright as warning fire. Orange orb rises colour leaps fish to her mouth and breath spreads to her gunwales.

Darkness flees day's first yellow blast: rush of bold light shocks her as beach rocks waken. She arcs, casts her needs to imagined sun's domain, inhales daylight like pleasing aromas.

Seas remind her of sedge, newly launched boats romance the fisher in heremerald hook on her line, she reels green light to her bosom, gulps it down, nets the prize of its song.

Dust tumbles out as she breathes low, arms raise unconsciously to blue sky as wind billows into her void, cleaning corners into velvet on her soul. Charged, her blanket heaps like seaweed on shore.

She smiles as gulls drift higher, higher to test purple sky, their shrieks settling to earth like spray. Her body overflows with heady salt-scent, prickle of dawn raising gooseflesh and nipple.

Neck erect, she's a painted masthead charging through chop, proud under white clouds and dancing seafoam. Plain breath swells inside, her body ripples like sails taking wind.

Beyond the rainbow in her mind, colours tumble like tide through her. Her hold filled as with catch, she pulls anchored feet free, opens her eyes to greet the place where she is.

the Roman in me

My right defense is drooping battles find me at every turn though my shield is cracked, my horse

lame from her endless gallop pulling a chemotherapy chariot against the scar on my breast and my shriveled

lymph glands which now swell.

My sword arm grows soft with yellow fluid, heavy muscles tire from ACT and I grow fat

from withheld liquid: my worst terror in all this for besides my dulling sword I had only my arms and hands.

there is no grace
in war: from my slowing
chariot I smell their sweat
see the gleam in narrowed eyes.

I am a shining gladiator, hungry to quash little enemies in my veins
I am not finished—at least one more flaming lap before my race can be declared over

rowdies and hoodlums

while I struggle to sleep after

hours of agonized restless limbs

bones and joints screaming with

every movement (must look like a

junkie, twitching like that, my fattened

face contorted and white as a card)

disjointed words all lanky and akimbo

each one eager to translate and

record my thoughts onto crisp paper

clamour on my bedroom threshold

noisy and belligerent as drunken thugs

watching buffalo in August

surviving this far, can I claim victory—should I dare—however temporary over that unending landscape so like wild plains of English ancestors fields once open, untouched, sweet-smelling save for thousands of buffalo carcasses which loomed like foreboding headstones in the serious dusk?

BC looks nothing but wet (snow lake, glacier, stream) during late-night flight with a movie of sunset: enormous horizon of soothing peach, smoky mauve from end to end over stretches of blackening black below

flying East, it hangs many hours against square charcoal clouds that resist whatever wind occurs. Into that hurtful red blaze I recline, romancing terrain underwing and flashing back to youth when my favourite novel was running away to wilderness and surviving alone

where would I stop if I disappeared into plain or forest?

below this plane moored in still skies of vodka and orange hues, I imagine rooms of logs: smell unfolding like river currents grey as wet pewter, settling into my quilts dank air lifting forest spirits while coyote calls sashay through cloudless nights

if I lived the wilds would I be safer?

I watch day closing out the plane's tiny window, an affront of red and violet crackling like thick frost against my clouding eyes. I could run to build and settle there, by turgid lake, there by simple stream, there beside sturdy slope – *no* – massive river snaking for miles, offers a shore to follow

like bison roaming, outrunning arrows and long-guns

why settle at all?

of love and sleep

when I sleep I hear gardens in my dreams, honey-makers hum in hot noon hours, gauzy sound lifts off rainbows of roses in lazy waves against a chorus of wrens, concealed in low branches

nests hidden by moss-green bark-green, sea-green leaves

restless constancy of breath, so like the dullness of day and night winter and spring, my uneven chest (a beacon of my sea) rises, retires, chases coral-coloured potential in daylight, blue-violet fantasy in dark

fortune allows me to wallow in this crisp now-ness

stilled in this sanctity, I cradle the modest shell of my body's togetherness, smooth ivory case around my very yolk, my soul a precious hatchling I fail to keep warm under down duvets and hedging sighs

<u>vista</u>

beneath curled light white quiet like canoes under water

resonance

for Mo and the others

the refrigerator runs almost silently, its soft peal stalks her from her kitchen the sandy-grey sound of infirmity

> hums against her timpani like jangling Jamaican drums dancers jerking, spicy ghosts possessed

intimates attend to weep at the foot of her bed, watch her change as fruits on her counter bowl of cannibalized mossy ghouls

henchmen spreading, creeping under her blankets

her chalked tongue thickens plump as Cornish game hen a delicate dish no longer, she drifts in dry dilaudid air morphine skies

clouds blistering with each minuscule noise

her universe contorts swift as melody despite the ethereal echo of that insistent preserver of food she does not want

<u>relapse</u>

rare nights I wake from my depth to find him sleeping behind me like a new lover, passionate and tentative, body cupping mine as if beloved, and I must remind myself this spooner is my Reaper.

the heat of my body soaks into sheets folds into blanket creases while his cool weight waits, calm and confident around my hips, dark abyss of his hunger still beating and breathing, seriously seeking, seeking my response.

prairie fire

The love of a woman
is the possibility which
surrounds her as hair
her head, as the love of her
"The Love of a Woman," Robert Creeley

the love of a woman taken to wife, to bed, to task as tenderly as brambles and wild roses beside a long road: flat, straight as an argument, weathers winters that bolster seasonal crops, for prairie sun

is the possibility which her husband considers given, as present as the sky or grain elevators blotting sections like blemishes while wind marks them, shifts grain like river-flow, invades their home and

surrounds her as hair
which defies plaits, though her
fingers weave through it; the farmer
envies its easy beauty, fears
the threat his machinery yields
to the stunning red crown of

her head, as the love of her hungers deep, chokes tender blades of grain, weeds not yet bloomed -she watches fallow fields on solitary mornings, stacks her dreams like logs in their hearth

A-wall

to the

of your

constant reloading

opposing guns.

thin soldier in green stiff wool reliving all the battles we've raged and fought over and over again against ourselves. Fights that made our hope fracture our goodness dig trenches our marriage dispatch troops to march ahead and behind, great legions of broken trust poor sight poorer health and clothing too light against such brittle war. So alone I lay and watch you strategize your lone bleak reconnaissance, stubbornly ignoring the incoming and invasive wave which forces me into another full surrender

Chapter Four

gentle radiation

science looms above me looking like a giant phone handset

from which I call God daily, hiss the name at the receiver hanging over me large as a sting-ray, cradling me flat

pancaked in discomfort for two minutes while I lie rigid and goose-fleshed, warned that any movement will cause damage and burn healthy flesh to death

I've too little courage left to deal with this over-bright room so I begin to confuse God with nothing while

rays char my lung, stroke my chest through the bolus, mono-note squealing like nails on a chalkboard as my skin

blisters a wordless response

September 7

(email to my husband)

Hi D---:

I'm having a little bit of a meltdown this morning after my radiation treatment because I met with the stand-in radiologist for Dr. Olivotto, Dr. Kadr, and he told me it was a great idea to take the Tamoxifen. Seems that if any breast cancer does spread through the blood it is completely *incurable*. What a horrible word THAT is! I really had no idea of this fact either. I thought that you just treated it again--like they just did to me. Shit.

I hate this. I hate the fact that I will forever be someone "living with breast cancer" like Dr. Kadr says. The medical practitioners consider breast cancer a life-long thing, even after you've done your treatment, even if they *got it all*. Apparently recurrence is rare, but it spreading to other parts of the body isn't as rare. And that spread can't be cured. The word "incurable" is hanging in the air around me right now, like a cloud of mosquitos.

I hate it. It means, once you break down my appointment today, that I will be taking the Tamoxifen for the next five years, after all. In the sixth year, Dr. Kadr says I'll change to taking something called Aromatase Inhibitors for another five years. I had hoped all the chemical stuff was over. I'll also do all the natural things I want to, but eleven years is a long sentence. Cancer is a nasty, fucking thing, but at least they can fight it. I can fight it.

I wonder if you understand? Somehow I feel I'm lonelier than I've ever been, sitting here at this public computer, just outside the radiation treatment room, weeping and writing. I mean, death takes many forms: out-of-control buses and things that bite.... But having some teeny cells in your body that may never be 'safe' cells, that's more shitty than I can tell you.

I really need a hug. Without questions, or strings, or sound, Just a deep and sincere hug. Maybe you can give me that when I get home tomorrow. I am so, so sorry that this is happening. I wish I were stronger, I wish I were healthier. I'm so sorry.

D

Mother

--for Wam

on this sallow-lit day when your body has been wrung out for its fresh water pearl, your shell too trusting to repel that singular, miniscule grain of cancerous sand which eventually overtook you: walk towards the warming sun.

on the eve of this first night of breathlessness when you stand alone from family and friends and enemies are mere shadows which fall across the threshold you have so recently and noticeably traversed: walk towards the warming sun.

into the silent embrace of an unknown realm where other souls dance like veiled butterflies over forever flowers, you are the newest voice, the freshest member to step from the yawning bay onto the clear beach: walk towards the warming sun.

your leaving brings wisps of fog which steal warmth and bring forth skeins of separateness that pale your brows and chill your hands--though your body is free, we picture your quiet feet: walk towards the warming sun.

in this new-dark day, I wither without your touch and grapple with a gnawing ache for your passage, but the courage you showed us Mother, fills our souls with sparkling light where over time it will pearl and spread: under the blaze of a warming sun.

afterwards

Another flood is coming though not the kind you think. There is still time to sink and think.

"Junkman's Obbligato," Lawrence Ferlinghetti

Another flood is coming.

current a tornado of white-blue foam and trumpet song, driven by an undulating wave to challenge the aloneness of acute illness—though not the kind you think.

the dammed-up river, thick as ancient cedars, surges past and through to unfenced fields, onto countless square acres of harvest. There is still time to sink

past your memories of muddied sloughs dense with cattails and goose dung, beyond where the moon calls with her voice of moths and think:

you are the churning, angry storm at the gate, life and breath are awake for your current overflows, swells with stubborn strength—and you are well again.

deep currents run smooth

for Candace

carry me overseas

- carry me like a prayer boat on a hot river where women with Turmeric skin and fuschia robes bathe, and wash their families' clothing
- carry me over vast blue-green expanses to view jagged ice in pallid blue, covered in speckled seals and yellowed bears
- carry me on waters running—
 hard as the Nahanni, over rocks and through
 chutes churning with foam and mortal danger
 light as the Seine, through a city at night whose
 lights burn lines onto the surface of the black
 snake's subtle current

carry me without the boat, without the paddle

- carry me to the lake of the monster where mist rises off churning grey-winter water like stalagmites and drips like stalactites from low-lying clouds
- carry me over the waterfall next to lilies large as pitchers white as lathered pearls
- carry me out of the hands of the land, into the arms of an ocean thick with purple starfish and shiny porpoises
- carry me through controlled chambers of the canal beyond grassy shores at the loch into the other world
- and in turn, I will carry your smile in my heart, safe as a flower, treasured as a tongue of rain

flat, round stones

Throw stones
Say anything
Blink at the sun and scratch
and stumble into silence
"Junkman's Obbligato," -- Lawrence Ferlinghetti

throw stones into my cleaned waters, don't

say anything to break the ripples' path

blink at the sun and scratch my name into this rock beach

and stumble into silence where bones and basalt meld

October 8, 2006

To all my family and dear friends:

It's time that I wrote a lengthy and informative letter to encapsulate the last year.

Hopefully, I can send it off and away, where I can imagine it so far removed that its content can no longer bruise me. That's my aim: to be over this year. Mind, I'm not unscathed, or internally/emotionally unchanged. I cannot fall into the same life I had before. I'm determined to keep my alterations constant: I have to take positive things out of this whole experience, and my alterations have been very hard won.

So, chemo was over in late July, and I started the radiation a month later. You may recall that my husband had planned to start his grad degree in August in Prince George, a city far from here, but he ultimately decided to put it off for a year. So I was able to complete my radiation treatments without having to watch him move away, mid-game. Now my treatments are done, and I am hoping we can learn to be a couple again (disease can certainly polarize people).

Life hasn't returned to 'normal' quite yet, but I'm back at university myself, trying unsuccessfully to will my mind to get over the chemical onslaught it has suffered in the last ten months. I'm not as smart as I used to be. My brain is cloudy on good days, but I no longer feel I have to be so darned serious all the time. I'm not sure my profs agree, or if my grades will be as high as they were pre-cancer, but I've lightened up. Sure wish I could have gone through this change in attitude without having the experience, but we all know that's highly improbable. Only with trauma do humans tend to *really* learn.

I learned a great deal about myself this past year, seeing as I had all that time to just sit still and do nothing (not something I was very good at before). But I also had a lot of time to really watch and appreciate friends, and the manifestations of the word friendship. I feel I'm changed by it. I'm more emotional than I ever was before (Oh no!!), but it's moderated by a keener, more palpable understanding of the human process and the arc Life takes.

Even though I'm still going through the emotional hang-over of this cancer experience, I laugh more than I ever have before. I see more beauty and have more awe than I ever perceived I would or could. I appreciate like I can't tell you! Just so you know, losing your hair (and I mean *all* your hair) is easy: it's accepting and celebrating the loss that is the harder part. Just remember as we age that Friends define you, not small things like hairstyles and job descriptions.

On that note, I thank everyone for keeping me in their thoughts and prayers, for making me soups and stews, phoning me when I was too ill to phone you, coming over to wax our floors, taking the dogs for walks, laughing at my stories even though they may not

have been funny, and not laughing at me when I made no sense at all. Thank you for visiting when I was healthy enough, and for not being offended when I turned you away because I wasn't healthy enough. Thank you all for listening. Thank you for initiating and pursuing me. And thank you for contributing to my healing in every way that you could.

To everyone, I can't thank you enough, nor can I explain how blessed I feel now to be here. Everyday IS a new day, filled with promise and excitement. I wish you all the best of these things, the ability to appreciate them, and the most love you could ever either give or receive.

Blessings and love, D

dear Dr. G:

You are a Doctor—a man in starched white tall and respected, leading a valuable life.

You are a Doctor—our first step against all the sickness that sticks to unsuspecting cell walls. Our bodies are bones, blood and bare, and you are our access to medical care.

You are a Doctor with a strong sense of Self; A costly education prevents your being wrong, and lawyers protect liabilities with arms this long. Yes,

You are a Doctor and know you know best, you know more than I'll ever see, because you went to Med school and have that degree that famed, framed paper hanging on your wall that gives you the gall to treat others small.

Yes, you are my Doctor; the one who pokes and frowns, presumes, projects, and postures me down because I'm just a girl, a student, a "thing" or whatever it is I do for a living.

Me? I'm your patient for five years a mere number on your list, a faceless, forceless receptionist despairing a condition you say doesn't exist. A woman who's fearing a silent disease: feels it conquering her way down, down deep--but you are the Doctor who looks with disdain when I come to your office again and again.

So when I finally fluke and see someone else, the sirens go off and it's all about my health. It's a freaky fucking roller coaster ride as a team of doctors widen their eyes saying I've only got six months, I'm so far gone maybe they can help but I've got to be strong it's a gamble at best and pray tell them why I didn't see a Doc sooner—do I want to die?

Their diagnosis is dire, I'm down to the wire so I end up afire for a full frightening year

with poisonous chemicals pumping in my veins being kept so close to death, it's absolutely insane, but I'm stubborn enough to take it and remain—I've got visions of Future visions of more visions that make me soulful and sore.

Like the one of you Doctor, with me in your space, making you look me right in the face as I form frozen words so true you can't deal so much truth it's painfully real: I am your patient

look at me!

I am every female

you will ever see. Pay attention, you must not deny and despite your ego, you must recognize young women can get cancer (oh dread!), and not all female patients are soft in their heads.

Receptionists, secretaries, gardeners, mothers lawyers, sisters, poets, lovers: they all have minds and know their Selfs, but they die prematurely when your righteous Self thinks only he's got a clue and only He can construe what's wrong with their beautiful bodies.

You were no longer my Doctor when I finally appeared in your office at the end of that terrible year... when I demanded you look me full in the eyes when you choked, sweat, apologized, and whispered you were absolutely surprised that I had made it and somehow survived.

You may be a Doctor, but tables can turn, and patients can know more than you, that we've both learned. You may be a Doctor, but we all make mistakes despite schools, status, income or stakes:

I was deathly ill for years and you missed it. Tell me, Dr. G —who *else* have you missed?

I appeal to you now Doctor, to check twice now even thrice lumps, moles, pains, and tears of patients you'll have in the upcoming years. I challenge you

Listen to worries and aches, nightmares and fears of every patient you'll face: don't let anyone suffer an assumption you make.

I am a patient, and will be 'til I die but it's my right to ensure you apologize that you question with caution that you listen and learn that you sleep well at night with respect you have earned.

Please. Ease your ego, champion your role accept there are things you may never know and my last words to you are these Dr. G: you'll be a better Doctor overall if you always just think

of Me.

Chapter Five

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.good.CHANGE.nothingness.careful.AFTER WORDS.sunshine.scar.l.scared.opportunity.
  .WHO.seen.music.friend.what.am.I?confusion.ugly.alarm.TIME.beauty.sleepless.
   .bewilder.DIVORCE.wonderment.POEM.awake.nature.BREATH.creative.silence.
   .door.SHE.daschund.softness.family.calm.never.song.moonbeam.SISTAR.craft.
     .learn.l.inside.WHERE.now.nutrition.me.prosthetic.bike.confidence.attract.
     .me.BELONG.energy.prettyshoes.coolshoes.awesomeboots.l.ALWAYS.oh!
      .parties.shift.fitness.whole.return.HAPPINESS.positive.sorry.DO.pain.fun.
      .PLAN.tired.travel.career.JOY.parents.regret.BE.story.dragonfly.growth.
       .school.solo.GO.fulfilled.$$.humour.realizations.SO.equal.honey.here.
        .YES.more.company.trust.awareness.laugh.blueberry.weddings.YES.
                        .quest.friends.snowshoes.discover.
          ١
                                      .LOVE.
                                    .l.
                                  .mine.
                                            .mine.
                              .Me.know.
                                            .l.race.be.
                           .soon.become.
                                           .longing.being.
                         .concert.ME.vibe.
                                           .two.degree.done.
                      .l.carnival.budding.
                                           .MEXICO.gardening.in.
                   .watch.flowers.picture. .remember.INSIDE.honor.
                 .bridges.adventure.dogs.
                                           .fingernails.proving.house.
               . topless.BECOMING.cradle.
                                           .employed.Christmas.LARGE.
             .wanted.sexual.think.games.
                                            .found.I.sky.hikes.balloon.cry.
           .teach.PLAY.shadow.champion.
                                            .REWARD.bravest.try.dreaming.
          .LUCK.realist.wine.fit.FLUEVOG.
                                            .colour.dynamic.TOGETHERNESS.
         .poetry.kitty.comfort.book.wish.
                                             .cause.BLOOD.renew.chance.ugh.
        .WOMANLY.light.wisdom.pedal.
                                              .assert.mountain.Tara.smile.WHY.
                                              .haircuts.children.ALLOW.paradym.
        .begin.pond.encourage.empath.
       .champion.PEACEFUL.mirror.
                                                 .saved.confidence.time.birthday.
      .SELF.ACCEPTANCE.MINE.
                                                        .SHARING.LOVER.FUTURE.
      I.GOODNESS.
                                                                 .US.BEAUTIFUL.I
     ı
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epilogue

cold that is endless starts at the top of the spine

cold this constant may always be mine

fatigue which assaults me day after day

I'm told is normal and may never ebb away

my memory is fractured, my focus gets lost

but in the interest of FUTURE everything's well worth the cost

Life is a gift which I partly control

and losing a breast doesn't make me less whole

although fear of recurrence may never abate

I will not wither, I will not wait

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