**6. Fun with Cancer Patients: The Affect of Cancer**

Brian Lobel

**Picture Your Life After Cancer**

In April 2010, *The New York Times Online* published ‘Picture Your Life After Cancer’, a user-generated photo essay collecting stories and images from cancer survivors. ‘For the estimated 12 million cancer survivors in the United States’, the feature begins, ‘some of life’s biggest challenges begin after the treatment ends’ (Barrow and Jackson, 2010). Although the feature recognises difficult consequences of illness, its focus is clearly centred on positive outcomes, asserting that ‘the cancer experience can lead to a shift in priorities, bring new insights or work as a catalyst to quit a job or try something new’ (ibid., 2010). The photographs deliver accordingly, with images of the Eiffel Tower, snow peaked mountains and cycling races dominating the landscape.

Accompanying the photo essay, readers are able to submit comments, most of which are devoted to individuals promoting their cancer blogs or expanding on the information in their photo submission. Inside these margins - perhaps tellingly ‘inside the margins’ - a singular voice challenges the presumptions of ‘Picture Your Life’ in a striking manner. In the pithiest response to the article, a woman identifying herself only as 'Claire' writes ‘Cancer ruined my fetility [sic] and my sex life. I was 26 when diagnosed. Life sucks now. Not what you were looking for?’ (Parker-Pop, 2010). Claire’s sentence rips through the photo essay and the bodies it features, which are healthy, fit and full of positivity. The statement draws attention to the un-photographable nature of her experience and alerts a reader to ask how a photograph of infertility or a ruined sex life looks. And if a photograph of this body, which is not healthy, fit or full of positivity were taken, would *The New York Times Online* allow it to be published?

Claire’s question is rhetorical, based on her knowledge of how positive messages around cancer are policed. Although her question presumes an individual experience, Claire’s singular voice is joined by a small chorus of commentators using her as a springboard for sharing. The formulaic nature of ‘Picture Your Life After Cancer’ seems to expect a certain type of response from its readership, tapping into the cult of positivity which is particular to public discussions of cancer treatment and cancer survivorship (discussed by Barbara Ehrenreich in Bright-Sided, 2009) and making limited space for alternative tones around cancer treatment or survivorship. More importantly, however, these projects limit what is really known about bodies with cancer, these bodies which are so often discussed but so often misunderstood.

**Fun with Cancer Patients**

The goal of my performance practice for over ten years has been to create space for alternative and truthful narratives around illness that promote reflection on how cancer is discussed, framed and read by audiences, particularly from voices which have been marginalized by either their content or their tone. In this chapter, I will examine two pieces that were created as part of *Fun with Cancer Patients* (FWCP), a project that was developed through two Wellcome Trust Arts Awards (2010 and 2013) and created in collaboration with Birmingham Teenage Cancer Trust at Fierce Festival in 2013. FWCP is an on-going exhibition project dedicated to raising the intellectual understanding of the cancer experience and, particularly, the experience of bodies with cancer. By taking as its subject the embodied reality of cancer – the smells, the annoyances, the pleasures, the absurdities – FWCP explores the psychosocial aspects of illness and provides patient participants with an opportunity to reflect on their unique embodied experience – and the wisdom that has derived from this reflection.

<insert Fig 3>

Figure 3. *Fun with Cancer Patients* website.

This chapter uses two ‘Actions’ from FWCP to illustrate how the embodied experience of cancer might be explored through performance – defined here as any live artistic action done for an audience of any size – in ways that free patients from cultural expectations of cancer survivorship. Drawn from interventionist methodologies and examples, the Guerilla Pub Quiz offers an unexpected representation of a cancer survivor, one that complicates the ‘burden of representation’ and that exposes the unknowability of cancer experience. The private action of Yoga at St Barts (‘performed’ only for an exhibition audience who witnessed its documentation) raises the question of who such performances are for, complicating issues around the intended effects and affects of performance. In both cases, the one-off Action is presented to audiences through their documentation so that it is primarily the documentation, presented at the exhibition, rather than the Action, which 'performs'.

The body with cancer is an unknown body, and a body that is essentially unknowable to anyone else, including an individual before their own cancer diagnosis. Lyotard’s differend, or ‘the unstable state and instant of language wherein something which must be able to be put into phrases cannot yet be’ provides a useful starting point for the unknowability of the body with cancer (Lyotard, 1988, 13). The body with cancer – particularly soon after diagnosis – becomes a body which does not quite understand itself. Although there are many things that disturb a body’s constitution and understanding of itself – ageing, accidents, violence, other diseases – the heaviness of the word cancer (and its position as something within the body which has grown malignantly and unnoticed by the body’s usual systems) causes a radical shift. And given that the body with cancer is a public body – diagnosis is often marked by a number of appointments, histories being taken, ‘comings out’ to families/friends/employers – there is an even greater imperative to put these feelings into phrases.

This relearning of the body is captured in crisp artistic language by photographer Jo Spence, who upon diagnosis with breast cancer, wrote ‘I realised with horror that my body was not made of photographic paper, nor was it an image, or an idea, or a psychic structure […] it was made of blood, bones and tissue. Some of them now appeared to be cancerous’ (Spence, 1986, 151). If Spence previously conceived of her body as a stable image or psychic structure able to be photographed, it appears that diagnosis demonstrated that artistic metaphor – even for an artist with a personally and politically-invested methodology – necessarily made way for bodily reality, post-diagnosis. And just as Lyotard discussed the urgency of finding phrases with the differend, the pressure for Spence to find these new ‘phrases’ (or artistic methodologies) forced new partnerships and new approaches to art-making.

Despite the intensity of the experience of diagnosis, and the medical and personal resources that seem to snap into high gear when an individual is diagnosed, the language around cancer still reeks with simple representations: either large-scale fundraising campaigns or inspirational tomes, none of which actually speak to cancer patients of the physical, emotional and/or psychological realities they are facing. Without any accurate representations or public conversation about the what, how and why of cancer, the body with cancer remains unknowable. FWCP queries bodies with cancer not only to make these bodies knowable to the broader public (thus injecting discourses with new information and new angles) but, most importantly, FWCP provides opportunities for the patient participants to make their bodies known to themselves, in whatever tone or format of documentation is appropriate and desired.

The process is simple: I work with a specific individual or group of patient participants to discuss what they want or need – in relation to their illness – and then work with them to create an extravagant Action to address this want or need. Previous Actions have included [pop-up kitchens](http://www.funwithcancerpatients.com/works/tell-the-kitchen/) and [far-flung car trips.](http://www.funwithcancerpatients.com/works/burn-baby-burn-those-newly-horrible-words/) Actions are then documented and displayed alongside critical reflections from patients and medical advisors on subjects such as post-treatment anxiety, the language of illness, [the development/loss of friendships](http://www.funwithcancerpatients.com/works/take-a-well-deserved-break/),[hair loss](http://www.funwithcancerpatients.com/works/use-what-you-got-and-what-you-lose/), decrease/increase of appetite and beyond.

I hope to demonstrate that FWCP may provide a space of engagement for those who find the tools established for the public exhibition of bodies with cancer (and bodies with histories of cancer) to be limiting and reaffirming of a policed positivity. I argue that the project opens up new spaces for expression to capture a patient-focused experience inside of performance creation and reception. By denying an audience an immediate interaction with – or story from – a body with cancer, and particularly with the smiling, fit bodies they are accustomed to seeing on advertisements for cancer fundraisers or inspirational stories, FWCP also engages with audience members’ distance from a one-off performance Action (instead being witness only to its documentation), as a metaphor for understanding embodied experience.

**Eat Me: Research, Development and Canvases**

By refusing to tell the story of a person with cancer from start to finish, FWCP avoids the dichotomy of Survivorship Story or Bereavement Story, which, as Jackie Stacey suggests, frames most cancer narratives (Stacey, 1997, 2). The performance and documentation process for all of the FWCP Actions derives from a reflection on the work of Hayley Newman, and in particular in her work *Connotations: Performance Images 1994-1998* (1998). The work, a series of photographs and accompanying texts taken from a fictional series of one-off performance events, highlights the tension between a performed action and its documentation and was, for Newman, a reflection on ‘the experience of performing and its archiving as a document’ (Newman, 2004, 166). What Newman does so effectively in *Connotations* is to blur or challenge the line between ‘truth’ and ‘fiction’ and ‘real- life’ experience and performance. Although the Actions in FWCP (described below) were very much real events, made by people affected by malignancies, the process of creating and documenting the Actions inherently blurs the line between truth and fiction. The private nature of these events and the subjectivity encouraged by documentation (which will be the only object available for public consumption) makes the borders between who is affected and who is not affected by cancer more porous — a useful place for FWCP to encourage its viewership to be when developing a more inclusive cancer conversation.

FWCP contained the explicit goal of creating ten different art objects, (documenting ten different Actions) which would be exhibited at the Mac Birmingham in the UK, exploring ten different psychosocial realities of cancer. The project sought to use Live Art methodologies to create discreet, one-off Actions that would offer new perspectives on the cancer experience. These individual perspectives could then be put together and, as a group, allow a complex, potentially conflicting experience for public audiences.

The tension between involving participants in a project, which is mostly centred on the increased learning of a ‘general public’ (unseen by participants creating Actions), brought significant challenges and it was ethical considerations which inspired the FWCP interactive Canvas, first created as a recruiting tool and later updated and exhibited as a hands-on exhibition piece. Graphic designer Nako Okubo, computer designer Chipp Jansen and I created a small activity that was capable of being both serious and playful in equal measure. The Canvas function consists of over 100 images, each based on a particular item from either cancer treatment or the embodied experience of illness. The images were derived from my own history and from cancer blogs and existing narratives. Traditional medical imagery such as x-ray machines, gurneys and nurses are mixed on the palette with images less-commonly displayed in relation to cancer, such as bed pans, amputated arms, vomit and marijuana.

Responding to imagery like that inside ‘Picture Your Life’, a stark black-and-white motif was chosen which, although playful, felt radically different from the colourful, yellow-ribbon-dotted pictures. Images were made malleable through a simple computer programme that allowed each image to be independently resized and repositioned. This simple tool allowed for a myriad of stories to be told and a number of embodied experiences to be represented. While pictures of cancer bodies are treated with a policed positivity, these black and white outlines of bodies can be flipped, stabbed and maltreated in ways which might be adequate metaphors for the cancer experience.

Upon seeing the Canvas depicted in Figure 4 during the research and development stage, I hoped that its creator would want to collaborate on an Action. Something about the Canvas’ gallows humour - an image of a skull being prodded by a fork, a knife and even a tea bag - struck me as funny and provocative. The image, for me, encapsulated the disempowering feeling of having your body prodded and poked by nurses, doctors and medical students. The accompanying text of simply ‘Eat Me’, however, pushed through the imagery in a manner similar to Claire’s response to ‘Picture Your Life’ in that it was bold, personal and undocument-able. The body, which actually experienced the shuffling and prodding, and which could never be meaningfully photographed, could here be represented metaphorically and presented (not as a body but as a set of ideas) for honest public dialogue. When Laura, the Canvas’ creator, emailed a few minutes later with an idea for an Action, our collaboration began.

<insert Fig.4>

Figure 4. Canvas Submitted to *Fun with Cancer Patients* website by Laura

In this chapter, I will consider two of the three Actions created with Laura as part of the research and development process (the other eight Actions are available on the online archive). I have chosen to reflect on the two created with Laura as they most directly reference the body with cancer, and particularly the known/unknown body. The two Actions I will analyze, Yoga at St. Barts and Guerilla Pub Quiz, most succinctly highlight the effort to challenge how traditional cancer narratives play with iconography and demonstrate how the process may open up new ways of seeing and engaging with bodies with cancer.

**Yoga at St. Barts**

For Laura, one of the most powerful, embodied experiences of post-cancer living was the nausea and anxiety that she would experience when leaving St. Paul’s tube station in London and walking towards the hospital:

I’d make that journey every time I had chemotherapy, knowing that I’d come to the hospital, be pumped full of drugs and leave feeling awful. So I’d start to feel sick even before I’d arrive at the hospital. There are little triggers along the way, the smell of the Café Nero, the smell of the coffee shop here, and the sound of the builders. All of these things helped trigger ‘Oh I’m going to the hospital. I’m going to feel really ill for the next few weeks’ (in Lobel, 2013).

As we reflected on this experience – an experience which I had not shared - the answer to the question ‘What would you do that would be helpful?’ always seemed to return to the hospital, and transforming it in some way. Yoga at St. Barts developed nearly instantly and organically: a sunrise yoga session in the middle of St. Bartholomew’s Hospital, for just Laura and an instructor. ‘The idea with the Action’, Laura stated, ‘is to make the hospital a safe place, a happy place’ (Lobel 2013).

In order to contextualize each Action into a conversation about cancer experience, the documentation of the Actions were discussed with Sue Gessler, a clinical psychologist working in gynaecological cancers. Gessler’s expertise was pursued to probe whether each Action represented a rare experience with cancer, or if other patients experienced the same realities. Gessler was asked to add professional context: Why do patients pursue activities such as yoga? Is it purely relaxation or is there something more at play? Gessler writes:

Yoga is about working the body, you’re breaking down the stance between mind and body. The body with cancer can become hated - patients will say ‘I can’t think about this part of my body’ or ‘I don’t think from here down’. Yoga is actually reconnecting people with their body in a more neutral way (in Lobel, 2013).

Yoga at St. Barts effectively highlighted the desire for calm, and a process by which post-treatment anxiety and discomfort with the body post-cancer can be addressed directly (even if for a day).

Gessler explained the Action without analyzing the ‘state’ of the participants. It felt essential that Laura’s Action be developed without pre-emption from a psychological professional, shielding Laura from what might be perceived as an overpowering medical system or policed positivity determining how her body needed to experience her cancer. With this process, the Action remained a yoga class between Laura, Angelika, Olga (who documented the work via twenty drawings in a sketchbook) and myself (audio recording the event). At no point was Laura asked to celebrate her survivorship or bemoan her body; she was not asked how effective this day of yoga was in reshaping her post-treatment anxiety. Instead, the Action allowed Laura to participate in something that fulfilled a particular need, while the performance for exhibition audiences (later looking at the drawings and hearing Angelika’s yoga instruction) provided an opportunity to reflect on how chemotherapy may leave indelible embodied memories.

The creating of distance for the audience is a conscious effort: not only does documentation remind the audience that they were not at the yoga class, but it also reminds them they are not necessarily privy to the emotional secrets of a person with cancer. Using twenty sketches and an audio recording as the documentation reinforced this distancing in that audience members could not always track the audio, requiring them to piece together the event themselves. The piece never claims to be Laura’s full story, but rather an attempt to intervene in her anxiety.

The Action’s privacy also demonstrates that FWCP does not propose to ‘help anyone’ directly, except those present. Although there is strength in community, there is something equally powerful in knowing that your life does not need to inspire others. In this way, FWCP achieves Arthur W. Frank’s goal stated in *The Wounded Storyteller* of shifting the ‘dominant cultural conception of illness away from passivity - the ill person as ‘victim of’ disease and then recipient of care - toward activity’ (Frank, 1995, xi). I argue that FWCP goes even farther than Frank’s suggestion by putting Laura’s Action in dialogue with Thompson’s idea of non-effect.

In *Performance Affects*, Thompson asks ‘How do we make work that is permitted not to promise  effect?’ (2009, 183). If the explicit goal of FWCP was effect, then the documentation of the work or its public iteration would demonstrate how much the various groups of participants learned, received or grew as a part of the Action-making process. Instead, it was FWCP’s affect on the exhibition audience that was the goal of the project, awakening, as Thompson writes, ‘individuals to possibilities beyond themselves without an insistence on what the experience is - what meanings should be attached’ (2009, 111). Because Laura was not asked to have her yoga class teach or do anything, Yoga at St. Barts - as an Action she created - empowered a truly active moment which, seemingly-ironically, effected nothing.

**Guerrilla Pub Quiz**

The Guerrilla Pub Quiz did not take the body of cancer patients as its central focus – instead focusing on the more internal phenomenon of ‘chemo brain’ – but featured a bold and (for audiences that were inside the pub and who later watch the documentation) uncomfortable presentation of a very empowered cancer body, one which was brash and outspoken, scarred and visible. In our preparatory conversations, Laura had talked extensively about memory loss or ‘chemo brain’ and questioned whether it was a real thing, or a convenient excuse for inattention. The answer, therefore, to FWCP’s question ‘What would you do that would be helpful?’ became ‘I would celebrate my memory loss’. And celebrate she did, with Guerilla Pub Quiz which was staged as an intervention at Off-Broadway in Hackney, London, with questions relating to Laura’s cancer. By crafting a competition in which competitors who answer the most questions incorrectly win, Laura flipped the expectation that to have memory loss is tragic. Guerilla Pub Quiz featured Laura’s stand-up persona, presenting material without reverential hush and, recognizing the usual severity around cancer, even provided an opportunity for audience members to rename cancer. ‘Last year’, she announced ‘I was diagnosed with kittens’. The Action, however, did not shy away from difficult territory, covering her presumed chances of survival, of recurrence and asking how many women were diagnosed with breast cancer in Britain each day.

Amidst a relatively fast-paced interaction with her audience, the question that caused the most commotion (to borrow usage from Sandahl and Auslander to describe the commotion caused by disabled bodies in public space (2005, 2)) was a question very few polite acquaintances would ask: ‘Which one of my boobs is fake, left or right?’ It was a complex question as it was said so proudly that the audience almost forgot that this was her body put forward for examination, her body with scars, with surgeries. Her body which is forever negotiating its ‘realness’ or ‘fakeness’ in front of strangers. While there are significant projects (particularly photography projects) which have taken on mastectomy scars as their subject, the appearance of bodies with breast cancer are still quite rare, and Laura here negotiated it powerfully. After asking this particular question, Laura invited the stare – and audience members instantly asked her to shake her chest. While she initially conceded and shook, she quickly relented, ‘That gives it away,’ she said.

The intense ‘visual engagement’ of a stare, Garland-Thomson writes,

‘creates a circuit of communication and meaning-making. Staring bespeaks involvement, and being stared at demands a response. A staring encounter is a dynamic struggle - starers inquire, starees lock eyes or flee, and starers advance or retreat: one moves forward and the other moves back’ (Garland-Thomson, 2009, 2-3). By recognising the give and take of the stare, Garland-Thomson opens up the potential for pleasure and equity (or if not absolute equity, some sort of parity) in the relationship. The existence of pleasure and equity marks quite a progressive step forward from the pervasive rubric of ‘the gaze’, which sees the relationship between starer and staree as inherently oppressive (Garland-Thomson, 2009, 10). While audience members were seemingly staring at Laura’s body in this moment, it is clear that the entirety of the question was a strategy for her to engage that stare – and to stare directly back.

The public nature of Guerilla Pub Quiz, as different to Yoga at St. Barts, was perhaps its most notable feature and the overwhelming majority of those in the pub were not aware that any event would be taking place. Guerilla Pub Quiz succeeded in bringing cancer (and a proud cancer body) to a space that is imagined to be cancer-free, in hopes of integrating cancer into everyday conversation. This integration is an imperative mission, but not always a painless process, and in a handful of cases, audience members at the pub were quite unnerved by the performance.

The reflections on the Guerrilla Pub Quiz by Gessler allows the pub quiz to speak to larger issues related to cancer while, again, freeing Laura from carrying the ‘burden of representation’ (Morley and Chen, 1996, 442). Gessler begins by drawing attention to why ‘chemo brain’ is such a misunderstood or under-researched phenomenon: ‘Chemo brain is really, really interesting because there’s been a long history of patients complaining about it and people rather ignoring it because it’s not ‘sinister’. Everything to do with cancer is ignored if it’s not about the illness itself’ (in Lobel, 2013).

Identifying the biases inside the medical profession helps the viewer of the documentation think critically about medicine and understand it as a subjective process, affected by funding priorities and cultural context. If the previous goal of oncologists was to keep patients alive at any cost, a phenomenon like ‘chemo brain’ may not be a priority of cancer research.

But chemo brain, if not a scientific fact, is a current part of cancer conversation. A statement from University College London Hospital’s Head Nurse, Anne Lanceley, elucidates this point, explaining that the term chemo brain is ‘generated by people with cancer talking to each other. It’s a cancer-sufferers or –survivors’ terminology which is not a medical language. It seems empowering that it comes from the grassroots and not that it originates from a doctor’ (in Lobel, 2013). The ‘grassroots nature’ of the chemo brain conversation frames Laura’s Action by positioning Laura’s experience as one of many, redressing the absence of concrete scientific answers to this phenomenon. Laura takes memory loss as a given, and seemingly does not care whether it is real.

By adding the contextualizing statements after the Action - and without Laura’s participation in creating them - the Actions feel like Actions. While the documentation and statements allow the research of FWCP to come to the fore, they do so only in the hope of reducing the pressure placed on the event itself. The pressure for cancer patients and advocates to create something useful or effective (which may be derived from a culture that looks to pity people with cancer and stare at their bodies, thus separating them out as different) remains very real indeed. The mixture of Action, documentation and reflection allowed FWCP to respond to individual desires, outside pressures and, perhaps, the individual desires to appease those outside pressures.

**Fun with Reflections**

Reflecting on Yoga at St. Barts, Guerilla Pub Quiz and the entire exhibition in Birmingham makes me feel both confident and unsure about my conclusions, in equal measure. While I am enthusiastic about the final documentation created from the Actions, I am wary about drawing definitive conclusions from the work, or at least too many of them. The Actions and FWCP itself were developed from personal experiences, reacting to what I had experienced and heard in conversation with Laura, as opposed to an extensively researched biomedical or psycho-oncological process. While my reading on cancer and participation in conferences over the years has highlighted for me the importance of thinking about ‘chemo brain’, the importance of yoga, support systems and the like, there was (and is) no checklist of ‘Psychosocial Aspects of Cancer Experience’ that needs to be addressed by FWCP. And yet, from a critical perspective, it feels as though the engagement enacted through FWCP comes as a direct result of reading and consideration of practitioners and theorists like Garland-Thomson and Thompson. I believe that the affect created for Laura, audiences to the documentation, the FWCP team and for me is demonstrative of what a conscious research practice might look like. Even this uncertainty, this celebration of the end of effect feels like an appropriate and accurate result.

In January 2011, *The Guardian Weekend* featured a cover story entitled ‘Cancer: the new normal’ with an image of a supermarket filled with bald customers. The article (an excerpt from Siddhartha Mukherjee’s *The Emperor of All Maladies* (2011b)) puts forward the provocative idea that cancer is a normal process, and describes how the disease is ‘stitched into our genetic being’ (Mukherjee, 2011a, 23). ‘The question’, Mukherjee continues, ‘then will not be if we will encounter this immortal illness in our lives, but when’. Such a statement does not fly in the face of cancer research efforts or advocacy campaigns focused at curbing exposure to known carcinogens, but does sit in stark opposition to features like ‘Picture Your Life After Cancer’, with its strong bias towards positive changes post-cancer. While these efforts may mean to inspire survivors or promote funding for research, they also increase a separation of the cancer experience - and bodies with cancer - from the everyday. Even if a ‘cure’ for cancer (an incredibly reductive term considering the ways in which cancer functions) is found in our generation, if the focus is only on survivorship and cure, cure, cure, so much of the messy, ambiguous, difficult embodied experiences may remain unspoken about and unspoken for. These unknown bodies – the focus of so much public attention – will remain forever so in their medical, psychosocial or emotional dimensions. Although FWCP does not use performance methodologies to cure malignant growth or to effect particular medical changes, it does attempt to impact the overall affect of cancer, to curb the very real pressures that keep those with cancer from seeing honest representations of their lived experiences and their bodies, bodies which remain a flashpoint for both public fascination and repulsion.

