

7.2 Proud Disclosures and Awkward Receptions: Between bodies with cancer and their audiences

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'No one will casually talk to me anymore...' Tig Notaro, 2012

In the 2014 film adaptation of John Green's young adult novel *The Fault in Our Stars*, the story's two central characters, Hazel Grace and Gus Waters, travel to Amsterdam as part of a Make-A-Wish-Foundation-inspired trip provided to terminally ill children and teenagers.¹ The pair walk to the Anne Frank House where Hazel Grace – who has weak lungs from treatment – learns that because there is no elevator, she must carry her oxygen tank up multiple steep staircases into the annex. Initially hesitant, Hazel Grace (played by the healthy-looking-other-than-nasal-tubes-and-short-hair Shailene Woodley) bravely (as the music tells us) manages her way up the staircase where, shortly after, she and Gus finally share their first kiss, while the voice of Anne Frank's quote, 'I don't think of all the misery, but the beauty that still remains' plays in the background. The kiss is not a little one, it is long and passionate and deeply fulfilling for viewers who have, for the hour prior, waited for the teenage romance to be consummated. As they pull apart, they are surrounded by Anne Frank House tourists who applaud them as the music swells. Gus bows to their small audience and the scene cuts to the couple having sex for the first time.

In Green's original text, Hazel Grace, the narrator, is significantly more critical of the space and place of their kiss. 'You cannot kiss anyone in the Anne Frank House,' she reflects, but then remembers 'that Anne Frank, after all, kissed someone in the Anne Frank House...'² By contrast, the film creates a seamless connection between kissing at the Anne Frank House and young (cancer) love. It is in the moment of applause that the self-interestedness of youth comes into direct contact with the expectation that cancer patients will be applauded for anything they do, and be seen as heroic for the cancer they battle.

This chapter will consider the tensions and possibilities which exist between the currently-distinct medical and social models of disability as they are applied to people living with cancer, and how contemporary artists are using the live space of theatre and performance to challenge, in the immediate, and ultimately reconcile these distinctions. I will

employ contemporary examples of live performance makers, in both the US and UK, whose interplay with audience highlights the dialogic nature of being a body with cancer in front of an audience, from Los Angeles-based comic Tig Notaro to Cardiff-based performance artist Emily Underwood-Lee. The choice of case studies is intimately related to my own cancer journey – I was treated for testicular cancer in the US, but moved to the UK in pursuit of universal healthcare and worked artistically with cancer as a subject in the UK where currently based – but there is also significant exchange (both linguistically and visually) between the two national cancer conversations. Through a consideration of Notaro and Underwood-Lee's work, alongside the writing of theorist Audre Lorde and photographer Jo Spence, both working in the 1980s, this chapter demonstrates that contemporary performance around cancer resists the more popular medical model of *cure cure cure fundraise fundraise fundraise*, and brings audiences together with cancer patients. Instead of just applauding 'patients' for simply kissing in a public space, audiences and artists together are celebrating a deeper understanding of illness and health.

As a young adult with cancer myself, although never with a terminal diagnosis, I experienced a strange relationship with the non-sick world, particularly as my cancer coincided with (then-unfallen-hero) Lance Armstrong's third Tour de France win in 2002. Casual conversations were filled with words like 'fight' and 'win' and 'beat this' and seemed to include both blanket encouragement – which derived from a socially-constructed lexicon of cancer empathy phraseology – and total silence surrounding unfixable or uncomfortable problems, including sadness, diarrhoea, hairlessness and other biological and psychosocial effects of cancer treatment. Although I never tried kissing boys in Amsterdam to see if audiences would applaud me, I was pretty sure, that with my bald head, sunken eyes and post-surgical hunched posture, I could have got away with anything. Critical of these automated applauses, my earliest performance writings about cancer (in performances *BALL*, 2003, and *Other Funny Stories About Cancer*, 2006) purposefully played with an audience's expectations of how a cancer patient should behave, or really, what a cancer patient can get away with. For example, *BALL* depicts a just-cured 21-year-old Brian wishing the destruction of eight-year-old girls competing against him in a Cancer Survivor Picnic

Hula Hoop Contest; *Other Funny Stories About Cancer* focuses on the misogynistic quest of Brian – in a story originally cut from *BALL* – to lose his virginity via any available woman's body.

I did not want to be on the receiving end of people's kindness, nor did I want to be stared at continually out of worry, or because my illness inspired others to live more fully and love more deeply. I just wanted to be in space with other people in the most honest and non-predetermined manner that I could without, as I called it, pre-praise, or the *a priori* approval and exaltation of all actions of all cancer patients. In this regard, cancer patients are quite distinct from those living with other chronic, serious or invisible illnesses and disabilities – such as HIV/AIDS, mental illness and epilepsy – who may face serious medical interventions in their lives, without either the patronising sentiment nor the financial or emotional support that pre-praise may engender. While this wish to be seen not through a pre-praising lens is relevant for many marginalised identities, very rarely has having cancer – as opposed to being black, being a woman, or being disabled – been understood as being a distinct identity in dialogue with audiences who may or may not share commonalities. While film and television have explored cancer as topics or plot devices on selected occasions (*50/50*, *The Big C*, and *The Fault in Our Stars* in just the past few years), this distinct relationship between the bodies with cancer and an applauding, caring or tastefully disengaged audience is something which live performance and theatre have been radically refiguring.

The current landscape of cancer is dominated by a number of distinct themes and characteristics including, but not at all limited to: gendered fundraising campaigns for gendered cancers (Movember, Coppafeel, Test One Two and many more); fundraising through physical challenges (Race for the Cure, Light the Night); and a policed positivity around mental attitude and survivorship, as documented by Barbara Ehrenreich's *Bright-Sided: How Positive Thinking is Undermining America* (2009), evidenced by Tara Parker-Pope's *Picture Your Life After Cancer* (2012) and LIVESTRONG, and specifically targeted by recent campaigns by Macmillan and Stupid Cancer. Controversies about cancer abound in the news in both the US and the UK. For example, recently in the US, Susan G. Komen's problematic relationship with branding and political groups seen as anti-women's health and/

or corporations whose products are carcinogenic. Pancreatic Cancer UK's recent and deeply unsettling 'I Wish I Had Breast Cancer' Campaign (2014) pitted different cancers, of various 'sexiness' or public profile, against one another in hopes of demonstrating inequality in funding and research.

Each contemporary cancer controversy is met with a firestorm of personal, passionate and often coordinated responses, with a handful of organisations and charities – such as the American Cancer Association or Cancer Research UK – quickly dominating the editorials, the tweets and the viral videos shared with urgency and high emotion. Just as those who participate in Movember or Race for Life often have a specific point of inspiration (an ailing friend, a deceased parent), the response to cancer (which gets played out mostly over social media and popular press) nearly always employs the 'I' or 'my' – the personal connection to illness being the prompt for the emotional or political interjection.

What nearly all of the current controversies and themes around cancer conversations share is the medical model of understanding illness and the need, above all else, to fix what is malignant (or broken) about the body and to get back to a normal – an understanding of the body which is stable, fixed and recognisable as healthy and high functioning. The Cure will find a way to stop the body ever being sick, and Living Strong will allow those with a history of illness to integrate seamlessly back amongst the non-ill majority, for example, a most popular goal which is only recently being reconfigured by organisations like Teenage Cancer Trust who are undertaking significant discussions about post-illness being a space of new normality.³ The central argument, however, against the application of a purely medical model to understanding cancer is two-fold: firstly, as argued by Siddhartha Mukherjee in *The Emperor of All Maladies* (2010) cancer is a completely normal part of our existence – it grows from our cells and demonstrates cells which have fought against mortality; and secondly, the goal of *fix and return to normal* is nearly impossible for all cancer patients – bodies are permanently altered, relationships are changed, sexual function often affected, financial hardships occur, permanent scarring dominates, and many remain on long-term chemotherapy or immunotherapy treatments.

As charted by Lennard Davis under the medical model, 'people with disabilities were seen variously as poor, destitute creatures in need of the help of the church or as helpless victims of disease in need of correction offered by modern medical procedures.'⁴ Sociopolitically, the medical model of disability was popularly seen as repressive and unhelpful, as it promoted the idea that all impairment was an impetus for medical intervention. Contrarily, the social model offered a new perspective as Davis writes: 'Not plagued by God nor beset by disease, people with disabilities were seen as minority citizens deprived of their rights by a dominant able-ist majority.'⁵ Understanding Davis' rubric for the employment of medical or social models of disability, it becomes clear how illness sits uncomfortably next to current disability discourses, especially with regard to his statement, above, about charity. While disability activists have demonstrated a difficult relationship with charity, cancer activists have embraced it and they are running for it,⁶ standing up for it,⁷ baking for it⁸ and even 'motorboating' women's breasts in public for it.⁹ Disabled activists eschewing models of charity – evidenced extensively in the writing of both Koppers and Rosemarie Garland-Thomson and the arts practice of Katherine Araniello (one half of Disabled Avant-Garde) in her performance *Charity Collection Doll* (2013) amongst others – are at distinct odds from approaches where charity *is* the modus operandi, both in terms of medical funding and ancillary cancer care. While in the UK, disabled activists treat the word 'handicapped' as offensive because of its relationship to the practice of enforced begging for disabled people, cancer patients and those raising money on their behalf seem very comfortable asking for money on the streets, or going door-to-door. While the political trajectory of the disability movement – from the Americans with Disabilities Act in the US to the Independent Living Fund in the UK – has embraced a wide range of individuals with a wide range of disabilities, the political trajectory of the cancer community has been splintered, particularly because of the medical model of understanding cancer. In hopes of fixing the problem and returning to 'normal', cancer patients have rarely fought for justice in the same way that individuals with disability have fought for more access and more legal protections. Even amongst cancer charities during the US's passing of the Affordable Care Act (2010), which greatly benefitted young adults with cancer and cancer histories, few voices were present or passionate. This lack of activism may have many different origin points such as the myopia which cancer

(through extensive and exhausting treatments) causes the lack of language to discuss cancer. It is clear, however, that a dependence on charity and goodwill (and a disinclination to alienate donors through controversial politics) demonstrates that the medical model of understanding disability, as applied to cancer, may – just as it did for disabled people – prevent particular forms of activism. This has not gone unnoticed by those critical of ‘awareness’-raising schemes such as pink ribbon campaigns, called out as early as 1998 by Sandy M. Fernandez in the now-defunct *MAMM Magazine*, who focused attention on the relationship between consumerism and fundraising, and the lack of metrics put in place to assess the efficacy of awareness raising campaigns.¹⁰

There are a number of clear and passionate outliers who have demonstrated that cancer patients can be ardent activists who are capable of embracing more than Talcott Parson’s passive ‘sick role’, which includes, as described by Arthur W. Frank, a patient’s full submission to doctors and their orders.¹¹ As chronicled in Mukherjee’s *The Emperor of All Maladies*, during the 1980s and 1990s, breast cancer activists were particularly emboldened by ACT UP and other HIV/AIDS activists who chanted ‘Drugs into bodies; drugs into bodies’ to insist upon easier access to chemotherapy and an end to extensive double-blind studies.¹² More than simply a search for a medical cure, these activists spoke passionately about health inequalities, particularly for women, and demanded more critical consideration of health advocacy, funding and treatment.

When a surgeon drew an X on London-based photographer Jo Spence’s breast – insisting that she have a mastectomy immediately – Spence leapt (for the first time of many times) out of her ‘sick role’ and into her position as empowered patient responding to top-down, expertise-laden medical treatment, as documented in her series *The Picture of Health* (1982).¹³ Cultural theorist and activist Audre Lorde, in the US, recalled similarly disempowering medical treatment: ‘Now that the doctors here have decided I have liver cancer, they insist on reading all their findings as if that were a *fait accompli*. They refuse to look for any other reason for the irregularities in the X-rays, and they’re treating my resistance to their diagnosis as a personal affront.’¹⁴ Spence and Lorde both wrote about their personal interventions in these processes – either engaging in alternative therapies or

refusing chemotherapy altogether. Both women exemplify the moments of rare and powerful activism which allies them to a social model of understanding disability – reminding their audiences (doctors in the immediate sense and later readers or gallery viewers) that the cure which they sought was part of a much larger tapestry of understanding civil rights – the rights of women, the rights of people of colour and the rights of everyone to determine what happens to their own body. Perhaps the most inspiring revelation of Lorde and Spence’s work was this specific breaking of the ‘sick role’ in which one is conceived of as only sick, only living in sickness and only dealing with sickness, to instead be full people who, despite illness, maintain their political sense of self and their other social identities. Not only were Lorde and Spence not *just* cancer patients, but they did not exist as cancer patients who could be easily applauded for simply being sick with cancer. Keenly aware of the gaze which stared at them, they both employed their work – photography and essay – to devise strategies to stare right back at audiences and those patronizing glances.

Garland-Thomson’s *Staring* chronicles the methods and strategies in which a number of people with physical differences and disabilities respond to the look of others, altering the usually oppressive situation of the gaze or the gawk to be something more dialogic, a relationship between ‘starer’ and ‘staree’ which is ever-changing and may contain the possibility of equality.¹⁵ Her writing provides an exciting starting point for understanding how cancer patients might also be reconfiguring their relationship to those around them who may be discomforted by their physical and emotional presence in a space. While most media representations deal with cancer as a singular subject, which is medical, needing to be fixed and which warrants pre-praise, both Notaro and Underwood-Lee are using the live body in live theatrical space to reconfigure a passive gaze, into a more strategic staring relationship: I see you, seeing me.

Los Angeles-based writer and comedian Notaro’s 2012 stand up set at Largo became an overnight sensation, with viral exposure and instantaneous praise from comics such as Louis C.K..¹⁶ Her bold approach hides nothing from her audiences, walking on stage and starting with:

Hello. Good evening, hello. I have cancer, how are you? Hi, how are you, is everybody having a good time? I have cancer, how are you? It's a good time. Diagnosed with cancer. It feels good. *Just* diagnosed with cancer. Oh god. Oh my god. It's weird because with humor, the equation is, 'tragedy plus time equals comedy.' I am just at tragedy right now. That's just where I am in the equation...¹⁷

The audience laughs with a palpable discomfort, seemingly unsure of the truth of Notaro's claims (But why would she lie?), or unsure if they should be laughing or even listening to this supposedly-personal, devastating disclosure. Notaro instantly picks up on the discomfort, and plays with discomfort, saying, 'Relax, everything's fine, I have cancer.' As she tells the story of her previous week, with familiar cancer plot points of mammograms, biopsies and pains, she returns to talking directly to an audience member: 'Somebody over here just keeps going, "Ooh, ooh, I think she might really have cancer." Who is taking this really bad? Oh, it's ok. It's going to be ok. It might not be ok, but I am just saying, "It's ok. You're going to be ok, I don't know what's going on with me." As the story unfolds, Notaro continually returns to the audience, their reactions to her tale – sometimes they laugh too hard, other times they are too nervous for her. While characters Hazel Grace and Gus took their audience's sympathy as a given, Notaro plays on their interconnection. When she announces that her mother has died (tragically, she adds) just months ago, the audience becomes even more silent, which prompts her to ask 'Should I leave? It's ok, you didn't know her,' and plays on the sympathy of cancer and of people's inability to take in too much tragedy at a given time. Instead of cancer as an isolated, medical issue, Notaro's interaction with her audience extends the frame, realizing the 'cancer patient' identity as one which functions in relation to others. Had her work been the pitch of a fundraiser or profile of a 'cancer patient', the focus of the story would be purely hers, but here Notaro is generous and dialogic: she uses the audience's groans and laughter as the subject of the comedy itself, alerting the audience to understanding that *her* cancer disclosure and *their* audience discomfort are both interconnected and funny. In other words, the humour and the discomfort are mutually reinforcing. As she finishes her set, she notices that the audience has become quieter. 'I really don't mean to bum you out...' she says, and asks, 'What if I were just to transition into some silly jokes?' The crowd yells a decisive 'No!' and she parrots right back: 'No, I want to hear more bad news! I'm sorry now that I don't have more bad news to share...'

Embracing the awkwardness of cancer diagnoses, disclosures and speaking about the unspeakable in public, Notaro has moved her audience from passive receptors of her *inspirational* cancer journey to become active allies who are supportive, critical and integral to the process of her coming to terms with this brand new identity. Without demanding a fundraiser or asking even for a cure, Notaro's comedy, and its live engagement with an audience, demonstrates the possibility for performance to move the cancer body from being something which is gawked at to something which is spoken with – and from the cheers and thank you's given from both Notaro and her audience, it appears that this speaking *with* is incredibly powerful and ultimately essential. Despite the fact that Underwood-Lee begins *Titillation* in a hospital gown, her performance remains far away from the medical model of understanding cancer. In the short performance, cancer is barely mentioned in its medical reality, but is instead linked into the process of learning (and unlearning, as she says) to be a woman. Like Notaro, Underwood-Lee is explicitly aware of her audience, playing and teasing with them about her breasts and their ultimate revelation.

As I said I'm here to talk about breasts, I've always thought my own breasts were rather fabulous. [*Cup breasts and strike a pose*] These aren't them though, these are the fake ones. I'll take them off later and show you. I lost the real ones. It's not really like I misplaced them [*Clasp chest – shocked face*]. 'Oh no – where could they be!' I suppose they were more taken away than lost. They've gone anyhow.

The revelation of post-mastectomy breasts or chest has been, and remains, an important trope in art about cancer (beginning with Matuschka's *Beauty Out of Damage* photograph for *The New York Times*, 1993,¹⁸ and including more recent works such as David Jay's *The Scar Project*, 2011¹⁹) and in cancer activism, with artists such as Tania Katan defending her right to run topless in breast cancer fundraising marathons (as documented in her book *My One-Night Stand with Cancer*, 2005²⁰). Nudity, and the revelation of the nude body with cancer, was a theme repeated extensively after introduced in Margaret Edson's 1999 Pulitzer Prize winning play *Wit*. In my own work, *BALL*, I joked with the audience about forthcoming nudity: 'I can't show you really [what it's like to get a genital ultrasound] because then I'd have to be naked, and I don't want to give away the ending...'²¹

Underwood-Lee's text looks less at her journey through cancer, or its related

treatment, and more through the process of becoming a woman, and, as she says 'forgetting how to be a woman'. She achieves this by linking not to the story of her own cancer, but to the story of Patrick Swayze, who died of pancreatic cancer in 2009. By charting her adoration of Swayze, and his heartthrob portrayal of Johnny Knight in *Dirty Dancing* (1987), Underwood-Lee removes the medical questions of cancer and leaves us, instead, with a thoughtful reflection on femininity, feminism and how women's bodies are seen and revealed in public space. The usual coyness around the nude cancer body may be exemplified by the final stage direction of *Wit* which reads: 'The instant she is naked, and beautiful, reaching for the light – Lights out.'²² In contrast, at the end of *Titillation* Underwood-Lee removes her false breasts (with tassels covering the nipples), removes her top, and simply stands in front of the audience. At Underwood-Lee's performance at *Fem Fresh* (Queen Mary College, University of London, 2014), the audience remained absolutely still during this final encounter with her body – it didn't demand an audience be sad about her body (and the soundtrack of Depeche Mode's 'Shake the Disease' distinctly meant to disrupt any kind of sympathetic reading), but the body also did not ease anyone's comfort about her life and future as a woman with cancer. Her final line – 'Patrick never got better and I don't know if I will, but right now, I'm still here' – exemplifies Underwood-Lee's deeply ambiguous ending image, which is more about presence and her changing body than it is about cancer and its treatment. This final image provides audiences with yet another new relationship with cancer bodies, one which bucks the trend of inspiring or cathartic narratives to one which is open, uncomfortable and un-ended. As perhaps a direct parallel to Underwood-Lee's open-ended cancer treatment, her refusing an audience the opportunity to feel wholly happy or wholly sad about her condition provides an unsettling portrayal which, much like Notaro's, tells us that we are all here together. We don't know where this is all going (the performance, the treatment) but we're all here together, and our potential discomfort with her lack of narrative closure, much like Notaro's play on the audience's awkwardness, is itself the aesthetic and political subject of this cancer performance.

The work of Tig Notaro and Emily Underwood-Lee, as well as that of Jo Spence and Audre Lorde, is applauded not out of pre-praise for cancer patients, but due to their radical

stance against the cancer patient being prescribed to their sick role, and their recognition that their experiences are inherently linked to how society views and discusses cancer. By observing their incisive artistic and theoretical outputs, possibilities abound beyond the simplistic models of *cure cure cure fundraise fundraise fundraise*, and a more critical approach can be taken to consider the content created by those experiencing cancer, currently seen as a place beyond criticality. While the social model of understanding disability has catalysed a community of empowered disabled thinkers and artists, the medical model currently burdening the understanding of cancer prevents the majority of patients to feel as though their experiences – outside the inspirational or tragic – deserve space in public discourse. Although young adults with cancer may feel thankful for *The Fault in Our Stars* taking on the subject of teenagers with illness, and many do, performers and thinkers who question the distance between patients and the expectations placed upon them to perform their illness in public space, provide examples for not only how to live sick, but for how the sick can live with those who are not. And, ultimately, for us all to live together.

¹ *The Fault in Our Stars*, dir. by Josh Boone (Temple Hill Entertainment, 2014).

² John Green, *The Fault in Our Stars* (London: Penguin, 2010), p. 202.

³ 'After Treatment', *Teenage Cancer Trust* (2015), <<https://www.teenagecancertrust.org/get-help/live-got-cancer/treatment/after-treatment>> [accessed 5 February 2015].

⁴ Lennard J. Davis, *Bending Over Backwards: Disability, Dismodernism and Other Difficult Positions* (New York & London: NYU Press, 2002), p. 12.

⁵ *Ibid.*, p. 12.

⁶ *Race for Life*, <<http://raceforlife.cancerresearchuk.org/index.html>>, [accessed 4 March 2015].

⁷ *Stand Up to Cancer*, <<http://www.standup2cancer.org/>> [accessed 4 March 2015].

⁸ *Break Through Bake Off*, <<http://www.breakthrough.org.uk/bakeoff/>> [accessed 4 March 2015].

⁹ *Motorboating Girls for Breast Cancer Awareness*, (2013),

<https://www.youtube.com/watch?v=AP8zXJ_xsEc> [accessed 4 March 2015].

¹⁰Sandy M. Fernandez, 'Pretty in Pink', originally printed in *MAMM Magazine*, June/July 1998, and available at *Think Before You Pink*, <http://thinkbeforeyoupink.org/?page_id=26> [accessed 29 January 2012].

¹¹Arthur W. Frank, *The Wounded Storyteller: Body, Illness and Ethics* (Chicago: University of Chicago Press, 1996), p. 81.

¹² Siddhartha Mukherjee, *The Emperor of All Maladies: A Biography of Cancer* (London: Fourth Estate, 2011), p. 319.

¹³ Jorge Ribalta, ed., *Jo Spence: Beyond the Perfect Picture* (Barcelona d'Art Contemporani de Barcelona, 2005), p. 268-280.

¹⁴Audre Lorde, *The Audre Lorde Compendium: Essays, Speeches and Journals* (London: Pandora, 1996), p. 290.

¹⁵ Rosemarie Garland-Thomson, *Staring: How we Looks* (Oxford: Oxford University Press, 2006), p. 12.

¹⁶ Neetzan Zimmerman, 'That Legendary Tig Notaro Stand Up Set is Now Available on Louis C.K.s Website', *Gawker*, (2012) <<http://gawker.com/5949371/that-legendary-tig-notaro-stand-up-set-is-now-available-on-louis-cks-website>> [accessed 2 May 2015].

¹⁷ Tig Notaro, (2012): *Live*.

¹⁸ Matuschka, 'Beauty Out of Damage' featured in Ferraro, Susan, 'The Anguished Politics of Breast Cancer', *New York Times*, 15 August 1993.

¹⁹ David Jay, *The Scar Project*, <<http://www.thescarproject.org/david-jay/>> [accessed 20 July 2015].

²⁰ Tania Katan, *My One Night Stand With Cancer* (New York City: Alyson Books, 2005).

²¹ Brian Lobel, *BALL & Other Funny Stories About Cancer* (London: Oberon Books, 2012) p. 14.

²² Margaret Edson, *Wit* (New York City: Faber & Faber, 1993), p. 85.