

Good afternoon. It's an honor and privilege to speak to you today. I've been performing at Find Your Sense of Tumour for the last few years, and have been performing my work on patient experience for the past 12 years, visiting nearly every country present at this Global Congress. So it's an honor, not just to perform as a uninspirationally inspiring cancer survivor, but to speak to you as a peer, as someone working in a slightly different kind of psychosocial care. I've been asked to speak to you on the Emotional and Physical Burden of Cancer, and, hopefully, to make it funny. If you survive cancer you can face any seemingly-impossible challenge, right? Well, here we go.

My name is Brian Lobel and I'm an immigrant to the UK. Thank you for having me here despite this fact. I hope you find that immigrants are welcomed for their opinions, expertise and contributions to UK society. And, as this is a World Congress, I hope you think this about immigrants and refugees everywhere, regardless of where you live.

I moved to London 9 years ago, before Healthcare Reform in America, as I had a preexisting condition and found that living in

the USA made me ashamed of my history with cancer from a legal and economic standpoint. While I received applause for my cancer survivorship at age 20, and people liked that I used my personal experience to humanize cancer patients for medical students and other health professionals – I felt a horrible disconnect elsewhere. I felt like I had to apologise for my health history to private insurers, I felt it strange to pay cash for cancer bloodtests (in hopes of keeping cancer off my permanent record), I hated that I still hated my body, and I hated being effusively grateful and thankful for everyone's concern and donations to cancer charities, when all I wanted to do was fade back into being the obnoxious man I knew to be the real, the authentic Brian Lobel.

I need to start a keynote talk with a conversation about politics because cancer *is* political. Louise Soanes mentioned it yesterday, and others have said it, but it bears repeating: cancer *is* political, it is affected by politics in real ways, and if we do not insist that cancer is political, we will lull ourselves into believing that cancer is apolitical. That cancer is an overall horrible thing that *surely* everyone wishes to fight, destroy, battle, and care for in the same way. If the elections of 2016 have taught us anything, it should be that we should not make any presumptions about our neighbours

or how they wish to solve the problems facing the world. If we think of cancer as apolitical, we will lull ourselves into believing that cancer patients are well-served by being the object of charity – they are not – and that cancer therapies and discoveries will continue to thrive despite government cuts – they will not – and that people with cancer are not affected by other institutional oppressions like racism, homophobia, religious discrimination, ableism, ageism and great economic disparities. They most certainly are not.

But now for a lighter topic: the Emotional and Physical Burden of cancer.

30, or now 27 minutes, on the topic of the burden of cancer would be impossible. Maybe it wouldn't be for a smarter speaker, but I'm not a smarter speaker, so it is for me, and I blame this squarely on cancer. It is big, it is scary, and in just two syllables, can make a person shut down, shut off, and disengage. The word itself is the biggest barrier to speaking on the burden of cancer because it means so many things in so many different ways. The word is the both the topic of intense fascination and vile repulsion. The word is

medical jargon, political posturing, ethical conundrums, personal traumas. The word is leukemia, melanoma, teratoma, mesothelioma, myeloma, sarcoma. The word is breasts, testicles, esophagi, bones, brains, ovaries, cervixes, retinas, pancreases, prostates, livers, colons, thyroids, and lungs. The word is “Am I eating too many eggs?” “Am I not eating enough eggs?” “Do I drink too much coffee?” “Do I not drink enough coffee?”

The word is Herceptin, Tamoxifen, Cisplatin, Bleomycin, Decadron, Kadcyla. The word is chemotherapy, radiation, immunotherapy, interventional radiology, BRCA1 and BRCA2. The word is Cancer Research UK, MacMillan, Teenage Cancer Trust, Maggie’s, Marie Curie, Tenovus, Teen Cancer America, Stupid Cancer, Canteen Ireland, Canteen Australia, Young Adult Cancer Canada, American Cancer Society, to name but a few in the English-speaking world. The word is Race for Life, Light the Night, Movember, Marathons, bikeathons, bakeathons. The word is JustGiving. The word is 4 cycles of treatments, 10 weeks off work, 100ml, 20 pills a day, 5 hours of surgery, 50/50, 6 months, 2-3 years. The word is No Make Up Selfies, I Wish I Had Breast Cancer Poster Campaigns, The Fault in their Stars. The word is Jade Goody, Donna Summer, Henrietta Laks, Lance Armstrong,

Susan Sontag, Stephen Sutton MBE. The word is hairlessness, it is malignancy, it is vomit, it is the suffering, and beyond suffering it is the death – and I don't know why we don't usually say 'death' but it is the death of people we love. If the word cancer is all of these things, and much more, it is no doubt that cancer itself makes it impossible, in, now 25 minutes, to talk about the burden of cancer.

For me, the main burden for young adults with cancer is knowing that this thing affecting their body is all of those things and more. It is the weight of the world's discomfort around bodies, discomfort around death, discomfort around not being productive, discomfort around people not looking their best. As a cancer patient, every cancer face that you see – serious, well-meaning, concerned and sympathetic – every cancer face you see is heavy with this discomfort, and that is a burden not easily shaken.

On November 1st, 2001, I walked home from the doctor after being diagnosed with Stage III metastatic testicular cancer and began writing what would eventually become the opening line of my first

play, BALL. “Problematic, I’m a 20 year old boy whose last concern should be bumpy balls. Problematic, a testicle as big and hard and bumpy as mine, I would say that’s something more than just problematic.” As you can see from the fact that I’m with you today, 15 years later, my cancer didn’t kill me so long ago, nor do I think it made me stronger, but it certainly did make me aware of both the physical and emotional burden of cancer.

The physical burden is always particularly hard to talk about because when the physical burden hits, it hits strong, and perspective or context are hard to come by. The body seems to destroy any ability to ‘remember this to reflect on this later’. Instead, you’re running to a toilet or a trash can to throw up in, or cozying up to a blanket, taking 2 morphine, binging on boxsets and dreaming wildly about Carrie Bradshaw’s shoes. Maybe that is just a little insight to my physical cancer experience. It was 2001 after all, and Sex & The City was critically and inextricably linked to both my pain and my recovery.

The physical burden seemed to destroy language in some way. In 2002, I tried to write about my recurrence of cancer, and the

physical shock of it all. After weeks of writer's block, I finally settled on something which, to this day, feels wildly accurate. I wrote:

My abdomen finally healed, and my remission lasted two months. And then the phone rang. There are no words to describe the feeling of being told that your cancer has come back. If there were words, or if there was something that I could do to show it to you, I don't think that I would. No one needs to see it. No one needs to experience that. I know that you want to know what it's like. We all want to sympathize or empathize or feel like we can relate or connect in some small way, but just don't. Please don't. There are just no words.

The reality was, though, in the moment of the phone call, and the diagnosis, nothing had actually changed – I didn't lose another testicle, I did not have my skin cut or tubes inserted. But physically, just as I had started to feel whole after my surgeries and chemotherapies, I found myself in a body which I didn't or couldn't understand. A body which had lumps which were hurting me. A body which needed immediate medical and physical attention.

But the emotional burden, that was the one that stuck with me – and still sticks with me today. As a cancer patient, I was regularly asked if I was feeling “back to normal”, as if Normal was a place I could go back to, as if Normal was a destination that, when I finally got there, would mean that all my problems, worries, fears and pains were gone. In my most generous moods, I understood that people asked this question because they cared how my body was feeling in relation to my treatment and that Normal, to them, meant healed, physically healed. In my least generous moods, I felt that people asked if I was back to Normal in the hopes that I would no longer mention my illness. That it was easier, and more pleasant for them, if we didn’t have to discuss it. That their reality wouldn’t have to stretch to include ill-health, fragility, vulnerability.

But I was never normal. And, after my experience with cancer, I began slowly slowly questioning why I had allowed such a concept to be so important to my life. I was always weird, I was always queer, I was always different, and quite proudly so. I wasn’t going to finish testicular cancer treatment and go back to being the well-behaved boy who plays sports and grunts. Although sometimes I grunt, I never played sports, I never was well-behaved. While the

trauma of a cancer diagnosis and treatment can make people grasp onto concepts and identities which feel well-understood, and use examples of survivors who are well-publicised and seemingly-together – for me, the pressure of normal became overwhelming. Although I'm sure that very few 20 year olds, even without cancer, feel normal in their own skin, the extremes of illness brought the stakes of normality into sharp relief. I found myself motivated to keep telling my abnormal story – to keep digging through the details of why I found myself abnormal – in hopes of creating a narrative which made sense, and which was comforting to my own personal development.

While I continued to think about what Normal meant to me, I was faced with a conundrum: how to write about an illness that a body no longer has. It had been 7-8 years since I had cancer in my body, new stories were growing infrequent, and even though I felt dedicated to still exploring the question of Normal for my body, I thought that I needed to think outside my own experience. Every thing I saw, though, confirmed that Abnormal cancer stories were rare, and that perhaps the inspiration and fundraising which are made capable by Normal stories are more important than me continuing to spout on and on about trying to lose my virginity

before surgery, or a strong desire to smoke in the hospital foyer.

What really is the point of sharing the weird, the marginal, the abnormal cancer stories.

And then I found a voice, in perhaps the strangest of places.

In 2010, *The New York Times* 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", it says, "some of life's biggest challenges begin after the treatment ends". Although the description recognises some of the potentially-difficult consequences of illness the focus of the photo collection 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". And most of the photographs deliver accordingly, with images of the Eiffel Tower, snow peaked mountains or cycling races dominating the landscape, each accompanied by 50-100 words of explanation.

In the blog below the photos, however, readers are able to submit comments on Picture Your Life After Cancer. The majority of these comments are devoted to individuals promoting their cancer blogs or expanding, in hundreds if not thousands of words,

on the information in their photo submission, which had been limited to 100 words.

Inside these margins — and perhaps it is telling that this exists inside the margins — a singular voice stood out. In the most pithy response to the article, a woman identifying herself only as Claire writes, “Cancer ruined my fertility and my sex life. I was 26 when diagnosed. Life sucks now. Not what you were looking for?” When I saw Claire’s short statement, I felt gut-punched, in a way which I hadn’t felt since after my retroperitoneal lymph node dissection. I felt this woman’s pain, her anger, and I identified with her — not for a ruined sex life — I’m fine — but with being the weird one, the obnoxious one, the contrarian one. I knew at this moment that I was not the only person who was negatively affected by the world’s hunt for Normal.

After seeing Claire’s statement in *Picture Your Life After Cancer*, I committed to — instead of doggedly going around telling my strange cancer tales — to collecting the contrary, the angry, the uninspirational voices of cancer. The voices so burdened by not only the physical thing of cancer, but also all of the bullshit surrounding it. So, I made shows where audience members touched my genitals so that they could reflect on their own

experience of having a body changed by time and illness, I made shows where audience members with stigmatized bodies sat in a spa and talked about feeling beautiful. I made shows where terminal cancer patients sought intimacy advice from sex toy sellers. I made spaces where patients could force their reluctant neighbours into a conversation about their health, or women with breast cancer histories could make online dating profiles that forewarned lovers about scarred bodies, or people could celebrate their chemo brain, or army veterans and cancer patients could play videogames against each other in hopes of finally determining who can battle harder. The more I celebrated with how not-normal other people were, the more I felt safe in my own sense of feeling like an outsider, an uninspirational cancer survivor.

And now, this is my work: to collect, support and promote the voices in the margin of cancer care and cancer society. Having found my people, I now work to introduce new voices who can speak on the burden of cancer, leaping out from the margins and into the spotlight, where their concerns can be seen by doctors, nurses, fundraisers, film writers, and policy makers. It's not always nice, and it's not always happy work. My oncologist from so many years ago visited London recently and he saw the musical that I

wrote about cancer with Bryony Kimmings and Tom Parkinson – entitled *A Pacifist’s Guide to the War on Cancer* – and he said “Ooh, it was very serious, and quite difficult. And you always seemed in such good spirits”. Yes, Dr., yes. My cancer was quite difficult. You got that right.

I’d like to show two short clips of such voices, the first from my friend Gia, who has a chronic soft tissue sarcoma, and with whom I attended a conference last year in Colorado where we smoked and talked about how marijuana policy affects young adults with chronic cancer. Upon hearing a rousing speech by a young, white, middle-class cancer survivor, whose cancer was – much like how cancer was discussed in the photo essay – a conduit for a fuller, more meaningful life, Gia pulled me outside (even without my tripod or sound equipment) and started to talk about privilege in the world of how cancer is discussed, even by cancer charities, and how this made her feel.

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And the second – for which you can tell I worked with a proper camera person – is from Lara, a young woman with Li Fraumeni Syndrome, who has just finished treatment for her 6th cancer before the age of 26. After asking to take her top off as part of a

public cancer event, Lara was rebuffed, made to feel ashamed of her mastectomy scars, and she decided that she needed to speak out about the still-difficult politics around gender, beauty and cancer. Many of you might know Lara, and she wanted to make sure you know that she has things to say on a great many topics, not just mastectomy. But this is one topic, on which she has a lot to say these days. Here's a video of Lara, who will take her top off in the video. That should not be a problem for you, but if it is, please feel free to close your eyes.

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I share and try to platform these voices in order to demonstrate that the world of Normal and 'getting back to Normal', and all of the burdens that come along with such a world - is still alive and well inside the cancer community, from fundraisers, doctors, nurses, caregivers – and even patients themselves. I feel like it is my job, and my mission, to expose these burdens - as uncomfortable as they might be – so that they are addressed by all the stakeholders surrounding cancer care. I know there are so so so many in the worlds of cancer who are looking out, researching and developing policy for those who fall outside the norm, and I have great admiration for their work, and I moved by what I've seen these

past few days. But I also know that there is resistance. And people protecting and promoting their brand, and people who think that cancer is best served by all of our positive thinking and community spirit. I'm not one of those people. I want cancer patients to be angry, dissatisfied, difficult to have a meal with, ungrateful...and I want them to be all those things, and healed, or treated with kindness in their death, and cared for, as well as possible. As Sue and Simon told you about the activity I do with anonymous questions, while I can accept reading a question like 'Why Me?' from a 13 year old with cancer – as this is an age-appropriate spiritual seeking – I cannot accept a question like 'How much money do I have to raise?' which I get which alarming frequency. I am afraid of a world in which patients must, as I did, be made to feel grateful, effusively grateful, for service and a dignity in care, which should be universal, or which we must fight to be universal. I'm not sure how many people are turned off by the policed positivity and 'return to normal' messaging of the world of cancer – I'm not sure if it's 1% or 5% or 60%. I'm also not sure if this is a discrete group of people, or rather an identity of perspective which people go in and out of at different times, with different treatment courses, etc. I'm sure a better researcher could find out, but I'm not

a better researcher, I'm just me. But what I can say, is that underneath Claire's statement in Picture Your Life After Cancer... are a number of more blog posts that each start with the words: I agree with Claire. While many are surrounding them were doing the same as others – promoting their own cancer blog or waxing lyrically about their inspiring life – all of these other people started their engagement with the site, by finding a voice which represented them. A voice who was angry, dissatisfied, unhappy, sad. You can almost imagine these people scrolling down the blog, eyes rolling, rage building, until they found a voice of relief. It's not the most happy of communities to be a part of... but it certainly is a community. And it only takes one bold voice to say "I am not Normal, perhaps I was never Normal. I'm not happy, and I am not afraid to say it". I hope we all promote that voice, or if you don't promote it, at least you listen to it and grow from its truth. I use a mantra with the young people at FYSOT. Repeat after me, if you like:

I'm not over it.

I'm not normal.

I'm not ok.

But I will be, soon.

But I might be, in my own time.

But I might be, by my own rules.

I fear I wasn't funny, like I wanted to be, like I often am. But I find the world difficult right now, and I know that the world of cancer – with its beyond capable professionals and amazing patients - are the best people in the world to promote a new definition of Normal – a normal which changes over time in response to new experiences and new information, a normal which is beautiful however it is, a normal which is socially just and inclusive. An understanding of normal which is not policing, but which is gentle, loving and kind. The emotional and physical burdens of cancer, of mental illness, of refugeeship, of police brutality, of disability benefit cuts, of 2016 – are many, but let us live in solidarity with all voices and lighten each person's individual burden, even a little.

Thank you very much for allowing me to speak to you today.