



Truth be told— perspectives on openness

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INTRODUCTION

Many dreams come true and some have silver linings. I live for my dreams and a pocketful of gold.

— Jimmy Page and Robert Plant

In the field of oncology, the timing and nature of difficult discussions can prove ponderous for physicians and patients alike. Barriers to speaking truthfully might be perceived, particularly when the patient is young. The two essays that follow demonstrate the different perspectives of a young man with cancer and his palliative care doctor. The writing process has afforded the authors valuable lessons in honest communication and the richness of discourse after open disclosure. There has been realization of the opportunity for truth and hope to coexist in the young despite the challenge of incurable illness.

JACK

I have had this piece of writing on my mind for about five or six weeks now. But today I put down the first word. I knew that in writing this, I wanted to be as open and honest as possible. For that, I knew I had to be in the right state of mind. I knew that, while writing, I would be dwelling on topics that will inescapably bring me down. But over the last couple of weeks, I have been feeling good. Really good! I've seen a lot of friends, played a lot of guitar, gotten back into cooking in a big way, and have all 'round been feeling healthy. While being careful never to delude myself on a daily basis, I guess I allow myself to be contented by the sincere and comforting lies of those around me. I change my way of thinking to a simpler version. I remind myself that one percent isn't impossible, and then I stop myself from completing the thought (as I would on any other occasion) with "But it is improbable." Today, I was told from a computed tomography scan that there is a chance my tumour has spread to a part of my brain. There

is no easy contentment for me right now. And I will write honestly for you.

When I was sixteen, I was diagnosed with stage IV Ewing sarcoma. A cancer that typically appears around puberty. Sixteen was actually unusually old for this disease. I was told that with aggressive treatment, I had a thirty or forty percent chance of being declared cured. I was also told that if I were to relapse, then my chances of being cured would drop significantly. So what I really heard in those first few appointments with my new oncologist was that I had about a sixty or seventy percent chance of Ewing sarcoma ultimately killing me. Heavy stuff for a sixteen-year-old to hear. I went numb for weeks.

I am now twenty-one, and after two relapses, high-dose chemotherapy, radiation, stem-cell transplants, and two surgeries, I am in palliative care. Honestly, I didn't know what palliative care was when I was told about it. I saw my doctor, Rachel, more than a few times before she kindly spelled out exactly what her job entailed for me. I was taken a little aback, but was not surprised. And I was very appreciative. Rachel is warm and comforting, but never gives me false hope. And I have never felt a shred of pity from her. It's obvious to me that that is a very difficult thing to do.

Having received such a dramatic diagnosis, I have had almost every person I know try to "help" me at some point over the last five years. My close family and friends have done an amazing job. I am consistently reminded how lucky I am to be surrounded with such loving and genuine people. But, on the other hand, I have had two people (one I never met) tell me that I'll be ok if I just change to an organic vegan diet and commit to regular enemas made from a special organic coffee. (Apparently the caffeine and antioxidants work better in your bum!) Most of these well-meaning suggestions I can just shrug off (and some laugh off!), but it gets absolutely exhausting dealing with these people, because most of them want me to be their version of hopeful. Which means I have to put on an act and tell sincere but

fragile people that I'm "going to make it." I do it to protect them. I do it because, if I tell the truth, they won't know how to react. Some will even refuse! Some will tell me that I'm not allowed to think that way and that I can never give up hope.

These are the extremes of course, but even the average well-wisher can be a tiring experience. Little phrases like, "I feel so sorry for you" and "My god, you poor thing" do nothing for my morale and remind me of things that I'm probably trying not to think about at that point in time. They sometimes cry, and they sometimes just ask me how my cancer is, and then go dead silent when I tell them. I've had people stare at me and stutter something along the lines of "that's too bad," and then change the topic with awkward and boring conversation.

The religious have done their best. They tell me they will pray for a cure. Or that I should pray. Or that it'll be okay because I'm a good person and I'll go to heaven and we'll all meet again one day in paradise. I'm not religious myself, but in those early days of diagnosis, I did pray. I prayed, and I wished for any sort of a sign. Days later, I was told that the cancer had spread to the pleura of my lung. Which to me said either there is no god, or worse, there is a god, and his answer to my prayer was a very loud, resounding "no." Still, I'm told there are people who pray for me every day. I appreciate the gesture, but I can't help but be somewhat dissatisfied with how they have chosen to help me.

The reality is, I am dying. Probably in the next few years. Probably after more debilitating treatments. And when it comes to the close, I will probably suffer, at least to some extent. And I wish I could talk about it more often. After all, I think about it every day. The concept doesn't scare me anymore, but it seems that most people around me are terrified on my behalf. There are so many meaningful conversations that I want to have with people that I never can. The topic just changes the way people think about me, and some treat me so drastically different after hearing the full story.

Rachel, together with my social worker Christina and the team at ONTrac [the Victorian Adolescent and Young Adult Cancer Service] at Peter Mac [the Peter MacCallum Cancer Centre] give me comfort and solace with my condition. They know all of the medical details that others wouldn't quite grasp. They know what my future will be like. They know how desperate and sad and painful and short my situation is. But without ever being unrealistic or instilling false hope, they somehow contribute to making sure I'm not a desperate or sad human being. They tell it how it is, no spin. Then they proceed to assure me that I can still do excellent things and be an excellent person. They encourage me to make my life, shall I say, more potent. And to enjoy everything I have the capacity to enjoy. Some days, this can be easy. Some days, not so easy. But I know they would listen to me on any day.

This piece may depress you, but I assure you, ninety-five percent of the time I am gloriously happy! I do a lot with my life. I make funky music, I laugh with friends, I cook delicious meals, and then eat too much and regret it instantly. I drive long distances to see incredible sights. I've climbed mountains and walked canyons. If I'm able, I will climb and walk more. I still occasionally flirt with a pretty girl, I stay out past my bedtime, and I sometimes drink a bit too much with good company. Just like any other twenty-one-year-old!

Though I deal with the heaviest thoughts about my future years on a daily basis, I try never to let that get in the way of today or tomorrow. At Peter Mac, ONTrac and the palliative care team help me with this. Usually in just a few short sentences. But they are the sentences that no one else seems to be able to construct, let alone deliver in anything but a dreary and depressed tone. And for this, I can't thank them enough.

RACHEL

This year, I have had the privilege of working as a fellow in adolescent and young adult palliative care at a well-regarded cancer centre in Melbourne, Australia. Jack was the first young patient referred to me in my new position (for management of relapse-induced pain). Surprisingly, despite my years of patient contact and adventures in medicine, I felt the nervous panic of inexperience. How do you act with young people? What language do you use? Should I behave like a "doctor," or do I pretend to be cool?

Being hip is relative. Despite the fact that I enjoy spending my weekends riding single-track on my mountain bike and being a (albeit old-school vinyl) DJ, I suppose to my young patients I appear, first and foremost, to be their doctor; straight-laced, approaching middle age, and extensively equipped with embarrassing old people jokes.

I've been fortunate to have had a wonderful career so far, including time as a flying doctor, providing aeromedical retrieval services to remote Cape York Peninsula. Palliative care is where I have settled, a field of medicine that allows one to be a fastidious practitioner of general medicine and an advocate for patients, and that affords the opportunity to be sensitive, adaptable, and at times, creative. My mentor wisely tells me that some of the best palliative care physicians come late to the specialty, with life experiences that augment the care of their patients.

Much has been written, often with eloquent sensitivity, about the challenges of providing care to young people with cancer—the unique physical and psychosocial characteristics that identify them as a very specific group in oncology^{1,2}. Armed with an extensive literature search on the communication issues pertaining to adolescents and young adults, I elected to offer nonjudgmental, confidential support

to Jack and his cohort of patients. I chose to act simply as myself, aware that, in truth, I have no idea how the cool people act these days.

During a very optimistic period in our therapeutic relationship, Jack and I decided to embark on a shared writing project documenting our successes. The pain that had initially prompted his referral had been successfully managed. He set about planning an epic road trip around our remote country with his friends. I helped him pack a medical contingency kit. We thought that that episode would be a good story to share. Some months later, though, at a more difficult time for Jack, we wrote these essays and can convey a deeper appreciation for the relationship of a young adult with cancer and that person's doctor.

Jack's writing communicates themes that we had not yet discussed in consultation. It is Jack, the patient, who prompts discussion of dying. In his essay, Jack mentions that the implications of having a palliative care doctor were not apparent at the outset. Indeed, I recall introducing myself as a pain doctor, somewhat apologetic for the fact that my title contained the word "palliative." My intention was protective, but experience has taught me the benefits of being more direct at the outset, regardless of the age of my patients. I am prompted to consider that a euphemistic approach erects barriers to communication. I now tell my patients that palliative care is here for the long haul, for all eventualities. And as I have gained more experience, I'm aware that young people accept this and are often reassured by it.

Jack gently implies that his mind has been occupied by more existential concerns than straightforward symptom management. This greater picture is obscured by a simple problem-solving approach. Jack's transition to this dialogue was facilitated by this exercise, an opportunity to write. I am humbled. I wonder if he would have sought these discussions earlier. Our consultations are now richer. We speak of the future, we talk about goals and legacies. We work in concert with the treating oncologist, as Jack continues with active treatments. We often consult together. We are open and truthful, and yet hope remains intact.

Palliative care is a valuable specialty, and I am proud to be a part of it. We seek to minimize suffering in people living with life-threatening illnesses. As practitioners, we must lead the way, dispelling the fears and negative connotations of the word "palliative"—more so now as we recognize our role earlier in the care of patients³. We endeavour to allow young patients to transition in their own time. The art is in recognizing when they are ready to talk. Sometimes they're ready before we are.

The future can appear bleak with uncontrolled symptoms; oftentimes patients seem to despair that they may never feel better than they do now. Achieving symptom control provides new hope, and gets young

life back onto a forward trajectory. With quality palliative care, Jack was back on his feet and better set up for the active treatment, which has continued to provide benefit. Our consultations are colourful montages of Jack's latest adventures, recipes, and music, balanced with talk of treatments and symptoms. I explain through pictures. He laughs at my lack of artistic prowess, even when the pictures are sad.

Jack has been my patient throughout this formative year. We have traversed peaks and troughs, shared wins, and sought ways to soften the blows of setbacks. As a doctor, I have grown and learned valuable lessons in providing care to his unique cohort of patients, who can often fall into the space between pediatric and adult oncology.

Sitting down with such an articulate, likeable young person to write about our experiences will be one of my enduring career memories. Most notably, however, has been the privilege of standing alongside this remarkably resilient young man during his periods of uncertainty and challenge. Honesty is paramount to young patients⁴. This year has taught me that truthfulness and hope can coexist. Jack leads by example, rebounding, relishing his life, eating, getting tattooed, taking care of others—all the while confronting the most profound of existential concerns. He has me listening to Led Zeppelin again. I am grateful, inspired. What lessons I have yet to learn.

CONFLICT OF INTEREST DISCLOSURES

The authors have no financial conflicts of interest.

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