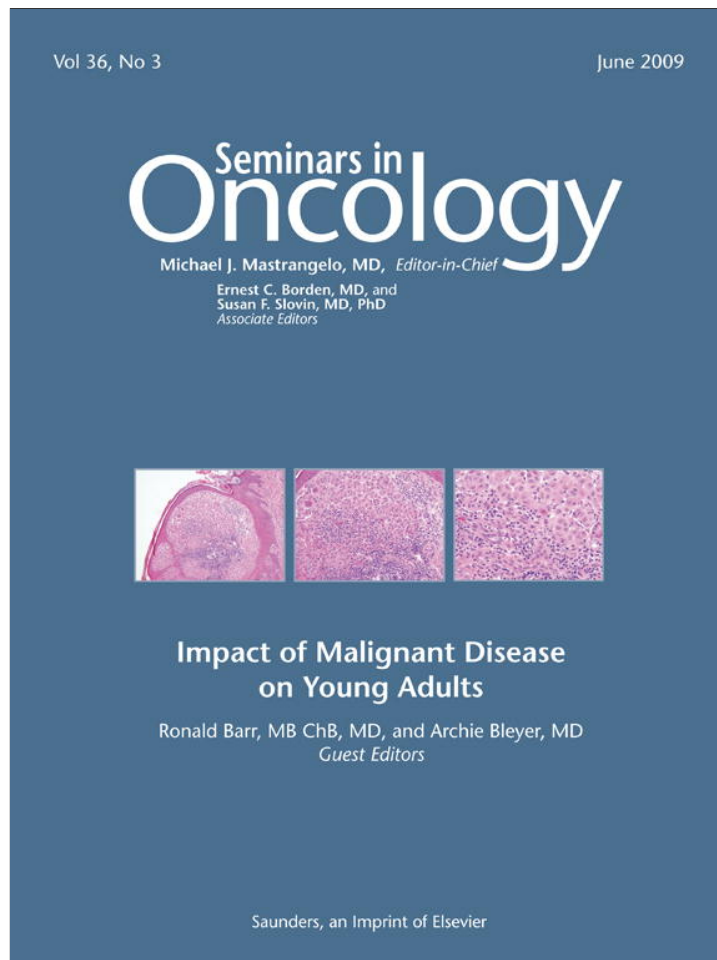


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# Identity, Image, and Sexuality in Young Adults With Cancer

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The impact of disease and treatment on a young adult's self-image and sexuality has been largely overlooked. This is surprising given that establishing social and romantic relationships is a normal occurrence in young adulthood. This article describes three female patients' cancer journeys and demonstrates how their experiences have impacted their psychosocial function and self-regard. The themes of body image, self-esteem, and identity formation are explored, in relation to implications for relationship-building and moving beyond a cancer diagnosis. This article has been written by young cancer survivors, Danielle Tindle, Kelly Denver, and Faye Lilley, in an effort to elucidate the ongoing struggle to reconcile cancer into a normal young adult's life.

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**D**uring the adolescent and young adult years, an individual defines his or her sense of self in relation to others. Their role in this "system" of relationships is affected by the bio-psychosocial developmental changes they experience, which interact to reveal a sense of identity.<sup>1</sup> This dynamic evolution of self-identification is therefore contingent upon one's experiences in the world and with other people. As a great deal of normal young adult behavior and thought involves social and sexual awareness and relationship-forming, a diagnosis of cancer, and its potential to isolate the individual, may interrupt or negatively affect this important aspect of young adulthood.

An experience of cancer in young adulthood irrevocably diverts the trajectory of normal identity formation. Through the treatment process, and the consequent bodily changes, a young person's physical self-perception may change from being sexual and potentially attractive to peers, to being sickly and degenerate. This affects not only their self-esteem but also their relationships with others. Relating to others and retaining a sense of normality are critical in the process of identity formation.<sup>2</sup> However, changes in appearance resulting from the cancer and/or treatment may negatively affect romantic relationships, and impinge upon a patient's sexual and social self-perception.<sup>3</sup> The feedback loop involving altered physical appearance, body image, social isolation,

and lowered self esteem causes particular distress among young adult cancer patients.

For the purposes of further understanding a young patient's experience of identity, image, and sexuality, three patient perspectives will be provided, spanning the time period prior to diagnosis through treatment and into survivorship. Patient narratives have been shown to be an effective method of identifying salient themes for young patients, as they powerfully depict cancer experiences on a very personal level, and in their own words.<sup>4</sup> This methodology is especially useful with such delicate topics as sexuality and identity.

Each of the authors had very different experiences of cancer, but similar themes can be identified. It will be seen how challenging it is for a young cancer patient to define a sense of self beyond the label of "cancer patient." This may impact their future relationships and ways of being in the world. Indeed, while sexuality and image are integral to a young person's psychosocial health and identity formation, health professionals often overlook the link between body image and sexuality.<sup>4</sup> Furthermore, studies have shown that alterations to sexual function and sexual expression occur in the majority of patients undergoing treatment.<sup>5</sup> For this reason, age-appropriate psychosocial support and, importantly, peer support, are essential both during treatment and into survivorship. From a patient perspective, recommendations for mitigating some of the issues faced by young adults with cancer are provided at the conclusion of this chapter.

## 18-28: TEN YEARS IN THE LIFE, LOVE (AND NEAR DEATH) OF A YOUNG WOMAN

Danielle Tindle

In 2002, at the age of 22, Danielle Tindle was diagnosed with Hodgkin lymphoma.

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Over the course of 3 years of chemotherapy, radiation, relapse, stem cell transplantation and liver disease, she transformed from an outgoing, sexually assertive redhead who loved to dance, to being emaciated, bald, and wheelchair-bound.

Upon recovery, Danielle translated her personal experience into the professional sphere and was employed by the Leukaemia Foundation Australia to research and develop a national education and support program for young adults affected by blood cancer. In 2007, she received a CanTeen scholarship to undertake an international postgraduate course in the cancer care of adolescents and young adults run by the Teenage Cancer Trust (UK).

Danielle also holds a Bachelor of Arts and a Master of International Studies. Her change in career direction is indicative of her passion for helping other young people living with a diagnosis of cancer.

It is difficult to know how much of my personality has been formed in response to my cancer experience, and how much is part of the normal "growing up" process. How can I extract one from the other, as both my identity as an adult and my identity as a cancer patient have been formed simultaneously? My trajectory into adulthood began when I moved out of my parents' home at age 18. It began fearlessly, recklessly, and joyously; nothing would stand between me and experiencing the world. I fell in love with abandon, drank too much wine, burned the candle at both ends studying hard and dancing the night away, back-packed through Europe, moved to Sydney from small town Brisbane, and felt beautiful, insatiable, invincible.

On a sunny spring day in Sydney, squeezed between a lecture in Human Rights and a romantic rendezvous with my boyfriend that evening, I scheduled an appointment with a specialist. Chest x-ray, blood tests, and a needle biopsy later, I was told I may have Hodgkin disease. I became "cancer girl" and for the next 3 years illness was my full-time occupation.

### *It's Libra, Not Cancer.*

#### *You Must Have the Wrong Person!*

After moving away from my friends and deferring from study in Sydney, treatment began at a major hospital in Brisbane so I could be cared for by my parents. Not only was my loss of independence a rude shock, but the physical transformation I experienced was, in every sense of the word, mortifying. As time passed, I no longer perceived myself as normal and could not

identify with peers. Indeed, my own physical appearance reflected in the mirror became foreign to me. Onlooking pitying gazes compounded this feeling of being "other," and led me to feel like a stranger in the everyday world, and in my own body. My body image affected my changing identity, and led me to question my sense of worth.

*"I'm not who I was, but cannot relate to anyone else; I don't know who I am becoming, or even if I will live. Who am I?"*

It is difficult for anyone confronted with such existential crises to reconcile cancer with a normal life. It is especially challenging for a young person to negotiate their identity and reconstruct their selves while navigating constraints, challenges, and interrogations, imposed by peers, family members, and the wider society. Body image is such a central aspect of identity development in young people.<sup>6</sup> An inability to relate to others because of bodily changes exacerbates this sense of identity loss.

As my condition worsened, so did my self esteem. This was compounded by the fact that I knew of no one my age who looked as I did. I perceived my frailty as a weakness and was reluctant to see friends who knew me as strong and self-assured. I was scared to reveal my physical deterioration when young women seem to aspire for beauty and vitality above all else. To this day I believe that not feeling attractive is one of the most psychologically damaging effects of treatment, impacting self-worth and social acceptance.

### *Does My Scar Look Big in This?*

To that point, my experience in the world as a physical being had been positive. I had plenty of male attention, loved experimenting with pretty clothes, and was competent at any sport or activity I attempted. My physical transformation crippled not only my abilities, but my identity as a woman. From being a flirtatious redhead, I transformed into a bald, skeletal, bright yellow "creature" that could not walk, was attached to a machine, and simply couldn't conceive of a future beyond a living hell. Tubes and scars covered my torso and chest, and I was constantly attempting to hide them with strategically placed accessories. I felt de-gendered and de-humanized; I was a cancer patient.

One would think that on the brink of death, appearance, sexuality, and the opposite sex would be far from one's mind. However, for a young person, establishing romantic relationships is one of the most important ways to determine one's identity. Although I had no idea whether I was to live or die, I knew that I wanted to be in love.

During treatment, I was fortunate to have a wonderfully supportive boyfriend. This relationship was my

life force, and his support, love, and encouragement is the reason I fought so hard. The promise of a future is a powerful thing and partners represent the prospect of a life beyond treatment.

However, this kind of relationship can be both wonderful and so difficult during this period. Young people are making sense of their bodies and sexuality and this is especially complex when faced with challenges to self-esteem, a lowered libido, and role changes within the relationship. Limitations on sexual function, whether actual or perceived, negatively affect a young person's sexual and romantic confidence. The question that plagued me was:

*“How can I be a sexual being  
and a girlfriend that he’s proud  
of when here I am, sick and bald?”*

While illness is considered to bring people closer together, this does not occur in all situations as expectations of each other and identities may change.<sup>7</sup> My boyfriend was my main source of social support, holding my hand during procedures, staying in hospital overnight when I was close to dying, and, importantly, helping me to cope and validate my experience. However, my 4-year relationship ended a year after treatment finished.

### ***Pleased to Meet You, I’m Patient 893084***

My status of cancer patient pervaded every interaction I had. I felt I needed to explain my experience when meeting anyone new. This necessity was almost a disclaimer, a kind of apology or explanation for my physical appearance and state of mind. I needed others to acknowledge my status as a cancer patient, needed them to know it wasn't my true self, that I was in fact better than all this.

During treatment, I felt the need to assert myself beyond being “just a patient.” The medical model, and illness itself, inadvertently disempowers patients of their humanity by forcing acquiescence to a medical authority, to those who know best. Young adulthood is a period of defining and asserting an individual identity and by the mere act of becoming a number in a hospital, this strength is taken away.

It is challenging to shake the label of patienthood after treatment has ended when this has been one's predominant role for so long. Perceiving oneself as a normal member of society, able to maintain normal relationships, may seem both impossible and, sometimes, treacherous.

### ***The Heavy Weight of Cancer Baggage (and Where’s My Big Strong Man to Help Me?)***

Following treatment, there was so much uncertainty beginning a new chapter with someone who did not understand what I went through, and even guilt for

leaving my boyfriend after he had looked after me for years. A young survivor may not believe that they will ever be with someone who understands and accepts them with the heavy weight of cancer baggage. The possibility of relapse is an ever-present threat.

*“Can what I offer in a relationship  
ever be as valuable as before treatment?”*

The prospect of having to tell potential suitors that I was a cancer survivor was a daunting task indeed. When is an appropriate time to disclose this information, and how does one go about it? There is no discourse for such a confession. Having to explain to a new love interest that:

- a. I've had cancer,
- b. What cancer is,
- c. What this means for me in the future and
- d. Potentially you.
- e. My infertility,
- f. My sexuality,
- g. My fear of relapse,
- h. And why I'm often tired.

It certainly makes a person dread this necessary conversation! Of course:

- i. How many dates should we have before I bring this up and
- j. Can you really deal with all this information and
- k. I'm sorry!

Young patients may honestly disbelieve that a potential boyfriend or girlfriend will accept them because of their physical and emotional cancer baggage. This concern, coupled with the fear that no one would find them sexually attractive because of their appearance, can pervade social interactions well into survivorship.<sup>4</sup>

### ***I’m Alive . . . Now What?***

For many young adults, survivorship poses new challenges when returning to the same world as a different person. To this day I don't know what my perception of the world would be as a 28-year-old woman had I not been diagnosed with cancer. The ongoing struggle of wanting to return to the carefree girl I was, coming to terms with a new identity, and grieving the woman that could have been, is confusing to say the least.

Furthermore, while the effects of treatment on reproductive health can be devastating, little is known about the psychosocial and behavioral consequences of infertility in young survivors.<sup>8</sup> I became infertile as a result of my treatment, and I had to come to terms with this not only for my own future but also for my partner's. I struggle with guilt and grieve a future lost.

Nearly 5 years in remission, I continue to deal with an altered physical appearance. Alongside scars from various lines and biopsies, I have permanent alopecia.

The further from the “honeymoon” phase of finishing treatment, the more concerned I was with how alopecia would impact my ability to form a new relationship. Various studies suggest that body image and self-esteem issues may increase further into survivorship.<sup>7</sup> While various coping strategies may be developed by young survivors to overcome other psychosocial concerns, appearance remains problematic.

It is an ongoing challenge to create an identity not associated with cancer, when to the outside world, I look like I'm currently receiving treatment. I feel that I need to explain that I am in fact quite well and healthy, thank you very much, and certainly don't need pity. Perhaps this is something I need to overcome so that I can be comfortable with my own identity and be less susceptible to the judgements of others. In my struggle to accept my altered appearance, I'm teaching myself to disassociate my worth as a woman from my appearance. A difficult task indeed, when society screams otherwise.

### ***Cancer and the Art of Tolerance***

For a young person, the knowledge of one's own mortality is a lesson learned too soon. Sure, it motivates us to live a more productive and healthy life, knowing that our time is finite and our health is precious; however, alongside this is the loss of feeling invincible. Fully coming to terms with the frailty of human life, at the tender age of 20-something years, means that the divide between you and your carefree peers deepens. In fact, “carefree” is a feeling that is rarely fully experienced again; an underlying sadness remains, a grief for the ephemeral nature of life.

This can be especially problematic when returning to the normalcy of society. Witnessing peers abuse their bodies with disregard and impunity seems a mockery of my survival. Life is so precious, my health is my priority and I need to feel in control of my body. While this might seem a noble pursuit, it does mean that I have different values from most people I meet. As time passes I'm learning to be tolerant of their health transgressions; however, with the relationships I've had post-treatment I've not been so kind. While my cancer journey has made me more compassionate, it also has made me more particular (again, whether this would have happened without my diagnosis, I don't know). Because life is so precious, and was so nearly taken away from me, I want to live it well. I feel that time is short. The person I choose as my life partner needs to share this love of life. Indeed, I believe relationships with friends, families, and lovers are the most important factors in a good life. After all, whether you're dying, or living each day as it comes, all that matters are the people that you love and who love you.

## **IMAGE AND SELF-ESTEEM? I'M A CANCER PATIENT**

**Kelly Denver**

Kelly was deputy head girl and a hard-working, eager student. She took three dance classes a week, had lots of friends, and had high aspirations for a future in primary school teaching. In 2001, Kelly Denver was preparing to take her A Level's and progress to university when she was diagnosed with non-Hodgkin lymphoma at the age of 18.

The intensive regimen of chemotherapy prescribed involved 3 months as an inpatient, neutropenic septicemia, biopsies, and lumbar punctures, followed by 15 months of outpatient maintenance treatment.

When Kelly finished her treatment in 2002, she entered the world as a different person, devoid of social skills and unable to find her niche. All this changed when she was introduced to the Teenage Cancer Trust (UK), a charity that allowed her to re-interpret her experiences as an opportunity to help other patients.

Six years later, Kelly has a Bachelor of Arts in Social Geography, teaches primary school children, and still enjoys working with the charity in her spare time.

### ***The Dreaded “C” Word***

Although I was a shy teenager, I had many passions and I worked hard to succeed in whatever I did. All this was shattered by a diagnosis of cancer at age 18. I became a cancer patient with no sense of identity, a person with a complete lack of self-confidence in who I was and what I looked like. The frightening part is that this happened without me even noticing the change.

Being told that I had non-Hodgkin lymphoma meant nothing to me, and I was quick to tell my friends that I would be fine. No one mentioned the “C” word until the second meeting, and then the bubble in which I had been living popped. I would be on an 18-month regimen—the first 3 months would be based almost solely in hospital and then the following 15 months would be spent on a maintenance regimen of treatment every 2 weeks. I left school immediately. I was no longer an 18-year-old female, I was a National Health Service number.

### ***The Visible Side of Cancer***

For the first 3 months I felt very sick and tired to a debilitating extent. I would lie during the day without the energy to hold a book or walk, although I was encouraged by my mother to do both of these things as often as possible. Yet at night I would lie awake, unable to sleep. I did lose weight but not to a dangerous degree; I suffered from mouth sores and very painful cramps, which remain unexplained to this day.

I just got on with these side effects. Sometimes, they were harder to deal with than at other times, and different chemotherapy had more severe effects. The only time that I contemplated my mortality was when I contracted neutropenic septicemia—I still find it a hard notion to accept that during my treatment I came closer to death as a direct result of a drug designed to make me better.

I never had to have surgery. I am not left with any scars other than from a Hickman line, but it does mean that as a survivor I have no visible signs of my illness and am therefore judged as fully recovered with no scars at all. That is far from the truth.

### ***The Hidden Truth***

The mental effects of cancer in my experience are far beyond any physical scars. They are evident during the treatment, although the patient is consumed with the immediacy of sickness, tiredness, boredom. When treatment is finished and the assumption of the public is that the patient is better, then the mental effects take precedence. Many young people who have survived cancer have reported a loss of identity as a result of their experience, and I also found that I almost forgot who I was. A mixture of isolation and poor body image caused me to isolate myself from society, and I found reintegration very difficult.

### ***"It's Only Hair—It'll Grow Back!"***

During the 18 months of my treatment I lost my hair seven times. Hair is an important part of how a girl feels and the choice of hairstyle is a sign of style and identity. Two days before I was due to start treatment I had my long hair cut into a short bob. I understood that having it cut short would negate some of the impact of its loss, but even before I had fully accepted my illness I felt as though I was broadcasting it to the world. It felt like an invasion of my privacy.

Waking up to find chunks of hair on my pillow compounded this feeling of losing control. I had a wig fitting, but I wore it once and it felt so uncomfortable and unstable that it has stayed in its box ever since. Instead I chose to wear bandannas; to me they felt more natural and less likely to fall off.

I stopped wearing makeup while I had my treatment. I was an 18-year-old girl, but I felt deeply unattractive and I didn't want to try to look pretty. I felt that

I could wait until I was better, but I couldn't face trying and being presented with my puffy face and bald head. I didn't care what I wore either. I would literally reach into my wardrobe and put on whatever came out.

This all sounds like I had become very depressed, which is not true. I just felt like my life was on hold, and I would wait rather than try to continue as normal. The result of the change in my image was that I lost all sense of my identity. To me, and as far as I was concerned to the public, I was no longer Kelly, I wasn't even female, I was just a cancer patient.

### ***"She's Doing OK"***

The loss of my female identity was no doubt compounded by the isolation imposed upon me by the treatment regimen. In the first 3 months, I was not capable of much interaction as I was so tired and sick that any time spent out of hospital was usually spent in bed. The difficult time was the 15 months of maintenance treatment in which the effects were lessened and I was much more aware of my surroundings.

I didn't have the opportunity to speak to my school friends about what was happening or to ask people to visit; all they knew was that I was very ill. As a result my close friends visited me at home, but other people stayed away. Hospital visiting was difficult because I was treated on an adult unit and was usually on a bay with three to seven elderly ladies who didn't appreciate my young friends visiting to cheer me up. It can't have been easy for my friends either, seeing their friend looking ill in such surroundings.

I was due to go to a sixth form party, but was prevented by a temperature of 40°C. To lessen my upset, several of my friends visited to show me their prom dresses. They changed in the toilet and paraded, albeit quietly, up and down the ward before sitting with me for over an hour. My fellow bay mates did not appreciate their efforts, although it is one of my favorite memories from that time.

The lack of visitors was made harder by very low immunity throughout my treatment. My immune system was constantly bombarded by the drugs and with the help of G-CSF I had about 4 days every fortnight when I was safe to be in public. Consequently I spent very little time with people my own age in the 18 months during which I was ill. My mother, who had taken 6 months off work when I was diagnosed, had to return to work during this maintenance period, which left me alone and tired in the daytime, with nothing to do but think. My sister quite rightly described me at this time as "19 going on 40!"

### ***The Middle of the Tunnel***

Over time I did become quite depressed. I couldn't remember who I had been before I had become ill and I couldn't yet see how I would emerge. I had lost the

ability to interact with other people because I rarely saw anyone but family. I walked around, on the rare occasions when I was in public, with invisible blinkers on, not seeing other people and only looking ahead. It was not a conscious decision to ignore people; I just gradually blocked them out. Looking back I think that I was afraid of what I would see if I saw someone looking at me. I had become so absorbed in my status as a cancer patient that I was convinced that was all people saw in me. I didn't even realize when people talked to me and my mom frequently had to talk for me.

Eighteen months after joining the cancer roller-coaster I finished my treatment because my white blood cell count could take no more. Of course I was overjoyed to have finished my treatment and the consultant considered my regimen a success, despite being curtailed. Finishing the treatment though was only the first step in my recovery. Until then my body had taken a physical hammering; now it appeared it was time for the mental impact to take precedence.

### ***Finished. Fixed. Next!***

The effects of taking months out of society were not to be removed immediately and I still struggled to be in company. I still wore my blinkers and found meeting new people incredibly hard. As a result of this, I found forming relationships, both platonic and romantic, very difficult. Firstly, I couldn't see why anyone would want to be my friend or would see me as attractive. I had very short hair, had become painfully shy, and was incapable of small talk. I didn't know what to say and I felt like a fraud if I hadn't told them that I had had cancer within the first 5 minutes; my loss of identity had been replaced with the identity of "cancer patient." Secondly, it was hard to trust people and let them into my life, as I was afraid of how they would react to my perceived history.

When I did start a lasting relationship, it was not due to my own abilities. When I met my now fiancé, I had to be told that he liked me by good friends, because I had taken all of his attentions as nothing but friendship—it had never crossed my mind that it would be anything more. Again, it felt necessary to tell him about my disease history, and I was surprised when his response was so supportive; why, I'm not sure. Equally, it felt imperative to discuss my possible fertility issues at an earlier stage than I might have otherwise, which could have put pressure on an early-stage relationship.

Six years on, I am more aware of these mental effects and am able to counteract them on many occasions, but my default settings are still towards low self-esteem and a lack of confidence in my own self-image.

### ***Making Sense of It All***

I made it through that treatment by a mixture of tired loss of concentration, drug-induced stupor, and

support. Throughout my treatment my mom was an unstinting source of support. I talked to her about how I was feeling and I couldn't have made it through the 18 months without her. Even to her though, my most trusted confidante, I was not entirely honest because I wanted to protect her from what I was really feeling.

I had become involved with the Teenage Cancer Trust (UK) during my treatment, as they had approached the hospital to build a unit for the treatment of 16- to 25-year-olds. I was asked to be on the discussion panel, and for the first time in months I felt as though my opinions were useful and pertinent; I became less of a burden. I met a few other patients and survivors of my age, and I realized through spending time with them that my treatment experience was not that different from that of others, and that they had come out the other side.

When I finished my treatment I spoke at their youth conference, which gave me a reason for having been ill. I spoke about my experiences to other patients and the response was phenomenal in that the audience was overwhelmingly understanding. Every person in that room knew what I had been through and empathized openly. That weekend remains imprinted on my mind as a time when my experiences began to make sense.

## **BODY ISSUES AND IDENTITY**

### **Faye Lilley**

In 2003, aged 21, just a month before completing a degree in Contemporary Arts at an English university, Faye Lilley was admitted to hospital for a routine operation to remove a blood clot. What the surgeon found however resulted in an open adrenalectomy and the diagnosis of a rare form of adrenal cancer, ganglioneuroblastoma.

Having gained a Bachelor of Arts degree, she now teaches dance in a private school in Derbyshire, England. Faye is also heavily involved in various projects and initiatives that raise awareness and concentrate on educating a public still largely ignorant of the issues faced by teenagers and young adults diagnosed with cancer.

Wherever we go in the world, women are constantly bombarded with images and ideals of what we should look like. The perfect body. A body that is toned, honed, tanned, slim, and blemish-free. We are conditioned to pursue the dream and all of us strive to a certain extent to fit in.

Like any 21-year-old I wanted to be "normal"; I wanted to "fit in." I had studied (and partied!) hard for 3 years and had almost completed my university degree. It had been

a period of self-discovery, making friends, maturing, and learning about my personal identity.

A month before my final exams everything changed. Out of the blue, after undergoing what I believed would be a routine operation to remove a blood clot, I was diagnosed with ganglioneuroblastoma, a rare adrenal gland cancer. All of a sudden my life was on hold. I was encouraged to forget about my degree and defer my studies for a year. I now had to watch those friends I had worked alongside getting on with their lives, happy, healthy, and competing for their dream jobs. I was concentrating on getting better and convinced I was being left behind.

I felt cheated. I recalled how the surgeon had demonstrated where on my body and how big my scar would be. Naturally I wasn't happy about acquiring a scar for the sake of a suspected "blood clot," but I was reassured by the nurses that my surgeon was not a "butcher" and that the scar would soon fade.

With my head still foggy from the anaesthetic, I remember sliding a hand under the bed sheets and placing it on my stomach. I froze as my fingers met a large oblong piece of gauze running the width of my middle. My mind instantly went into overdrive, imagining what was under the gauze. "Well it looks a bit like a 'smile'" a physiotherapist told me. "A WHAT?! A SMILE?!" "Yes a smile . . . if we hang you up by your feet," he replied. If this well-meaning but flippant comment was a light-hearted attempt to make me feel better, it missed its mark.

I had to wait a further week before I was given a glimpse of "the smile." As a nurse carefully peeled back the dressing, I watched as an ugly bruised line appeared. I was devastated. How would I ever get a job in performing arts now? What man would find a woman attractive when she looked like she had been sawn in half?

It wasn't until a further week had elapsed that I was told the surgeon had in fact removed not a blood clot, but a large tumor from my abdomen. As crazy as it may sound, at this point I was still more concerned about the scar. I hated the way the cancer had disfigured my body, hated the way it had left such a big mark on me, both physically and mentally. I felt like a Raggy Doll.

As a young woman I was still discovering who I was. The way I looked mattered greatly to me. I didn't want to stand out from the crowd because I looked freakishly different; I wanted to be like my peers. I was convinced that now I had a massive scar men would run a mile before getting involved with me, not only because of my body but because getting to know me might be a short-term thing. Would they take the risk that I might not still be around this time next year?

It was the early days after abdominal surgery that left their mark. My university friends and I had just completed our degrees and went on holiday to celebrate. I was still recovering from the surgery and really wasn't

well enough to go but persuaded my doctor the break would be good for me. I needed to regain some of my independence, make my own decisions and feel like a young woman instead of living in a sickly body that I felt had betrayed me.

While I was resigned to the fact people would notice my tummy while I was in a bikini, I hadn't prepared myself for the stage-whispered comments I would hear. A group of women on a beach one day didn't even bother whispering. Instead, holding their conversation like I didn't exist, they discussed loudly what they thought might have happened to me and remarked on how bad the scar looked. I was distraught. I have had three further cosmetic abdominal operations since the original surgery. I have even tried cosmetic camouflage but it left me looking like a piece of mouldy bread!

Despite the personal inner battle I have with myself regarding body issues, to the outside world I look normal. (I hope!) No one would guess the roller coaster ride I have been on because I blend in. I am hiding something that is easy to conceal, and I have become an expert. However, I knew a time would come when I would have to let my guard down and explain my insecurities. It concerned me how, when I did find a partner, I might broach the subject and judge the time was right to reveal the hidden physical and mental scars. I assumed because I was appalled by my ugly scars, everyone else would feel the same way.

Initially it is hard to realize that despite having cancer, you are still *you*. For a time I felt like a spectator in someone else's life. It was as if my previous three-dimensional identity had been stripped away from me and now I was reduced to a two-dimensional form: "that young woman with cancer." I think cancer patients give themselves a hard time and I've often thought, "at what point are you going to give yourself a break?"

Until I met my partner 3 years after my diagnosis I don't think I ever did give myself the breathing space I desperately needed. From the start of the relationship I found it strange that after years of people staring, he didn't seem to bat an eye at my scar. In fact the first time he saw it he knelt down and kissed it. I was totally stunned. I am certain it is his attitude that has helped me to feel more comfortable in my own (scarred) skin. To him it is part of who I am and a part he loves. I don't know if I just am lucky to find a man so understanding or whether his reaction is simply "normal" and I have been creating my own demons as to how men might react to me.

My partner even picks up my vibes when I slide back into the old habit of hiding my tummy on the first few days of a holiday and tells me to behave! He believes having cancer has acted as a handy filtering system with regard to finding a partner. Maybe he is right. I still have my body issues but slowly, with his help, I am starting to overcome them.

Without doubt, having cancer has had a big impact on me mentally and physically, but it is all too easy to simply see the negatives in such a situation. I have learnt a lot on my journey. I am far less superficial in my outlook and far less judgemental of many situations, including how I believe people perceive me. If a person is genuine, it really doesn't matter.

It has taken some time for me to love the new "modified" me. While I do not like to use my scar as some sort of psycho-babble "badge of courage," I do regard it as a form of my identification and I suppose it has shaped to a certain extent the person I am today. Without warning, the Raggy Doll in me still resurfaces from time to time, but I am improving. Let's be honest: who doesn't have insecurities?

## CONCLUSION

To assume that a patient is ready to be fully discharged when the treatment regimen is finished might be physiologically correct, but it takes no account of the psychological distress caused by such a debilitating, isolating, and often long treatment period. There is long-term support for late effects experienced as a result of treatment; however, support services rarely cater to the psychosocial issues of survivorship. Changes to a young patient's psyche or self-esteem may not be evident upon discharge, as many issues only manifest after treatment and may linger for years.

The three patient journeys in this article have demonstrated that although an individual's experience of illness is unique, common themes are evident in survival stories. Removal of normal social interaction with peers and imposed isolation is deeply unnatural and can be detrimental from the perspective of identity formation and preservation. Equally, the impact that treatment and isolation have on body image remains long after the cancer is gone, and should not be ignored. Appearance distress is often overlooked by health professionals, which is somewhat surprising given that body image is one of the greatest sources of ongoing distress in this age group.<sup>9</sup>

Throughout treatment, patients need to have the opportunity to interact formally and informally with other patients and survivors so that they do not experience such a degree of isolation. There also needs to be the opportunity for patients to remain connected to the outside world throughout their treatment and have new experiences, so that their known world does not retract to the walls of the hospital. These experiences need to take place alongside other young patients and former

friends as often as possible, so that contact with the patient's peer group is maintained. The peer group and the paraphernalia that accompanies young people are invaluable for the preservation of identity, yet sterile hospital wards that are not age-appropriate do not support this essential psychosocial requirement. Furthermore, self-esteem and body image may improve if young patients are treated alongside peers with similar appearances.<sup>4</sup>

By attempting to maintain normalcy, and yet allow the patient to feel confident in his or her situation through interaction with other people, both platonically and romantically, social confidence and identity may be preserved. As a result, the young patient may be able to effectively reintegrate into society because s/he has not lost contact to such a degree. Without the hospital environment actively encouraging peer support, relationships with former friends may be irreversibly affected, and new platonic and romantic relationships may be difficult to instigate. It is essential that a model of care designed for young people with cancer factors in age-appropriate psychosocial support, peer support, and mechanisms to maintain normalcy, so that the unquantifiable impact on identity, image, and sexuality can be minimized.

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