



CHAPTER 3

Cleone's Story

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SKIN DEEP

When I was five years old I started to develop a skin disorder, vitiligo, which caused a lack of pigment in my skin. As I got older the vitiligo spread. I was teased relentlessly by an uncle who amused himself with the thought of my skin having different colours. He decided to call me chameleon. This had a huge impact on me and at a young age I realised I was different. In my pre-teens I became extremely self-conscious. The white patches on my face became more noticeable, especially in summer as my natural skin colour tanned. My knees and elbows were completely white and I received constant unwanted attention. I routinely covered up the marks with makeup. When I ran out of makeup I hid my skin by wearing thick stockings and long-sleeved tops even in the heat of summer. Over the years I saw numerous specialists and was treated with copious amounts of oral and topical medication which seemed to work as the pigment in my skin gradually returned. At the age of 13 most of the pigment in my skin had returned. For the first time, I didn't need to cover up and looked forward to having bare legs in summer like any other teenager. To make them look even better I decided to experiment with hair remover on my legs. I did not know any better. I did not know that

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the side effects of all the medication had led to a drastic thinning of my skin. I did not know that my skin was extremely delicate and sensitive to chemicals. I did not know that, as I removed the hair from my legs, I would be removing the skin as well. The ordeal caused third-degree burns which were excruciatingly painful. I was crushed. My legs were permanently scared. My self-confidence was non-existent and my self-esteem was at an all-time low.

AS A YOUNG ADULT

Due in part to these early experiences and the resulting scars, I never thought of myself as beautiful in the traditional sense. I was too skinny, my breasts were too small, my hair too curly and my features unrefined. I was conditioned to think what a woman was supposed to look like, and I did not fit that mould. I was quiet, an introvert, extremely self-conscious and had low self-esteem. Even so, I understood that there was something about me that made me attractive to other people. I was well-liked, even popular and accepted in the “in crowd”. I did modelling and was able to hide my insecurities with a mask of confidence that emerged through being a model, although the confidence was never truly there. This facade worked for many years. The make-up, hair, clothes and parties were wonderful - they hid the insecure parts of me and boosted my self-esteem even if only for a while. But I always questioned if there was more to life than the show, the fashion parade of life, the polished external that was required in order to fit in. As much as I needed this experience to feel accepted and validated as a person who was outwardly attractive, I recognised the superficiality of it all. There had to be more to life than what was seen at face value. It had to be more than just skin deep (Image 3.1).

LIFE BEFORE DISABILITY

My life before was very different. In the months and weeks before the accident, something changed in me that led me to see life in a new way, in a new light. I remember being so grateful for being alive and for having a healthy, beautiful body. I started really appreciating things that I had previously taken for granted, like being able to see the sky that was so blue and clouds and trees. I remember waking up in the morning and going outside to see the sky and being thankful for this. I remember taking deep breaths, filling up my lungs because it felt good. Trees and plants



Image 3.1 Skin (Photo by Amin Arnold Gray)

especially seemed to come alive to me and I realised how marvellous and splendid they were. To be able to hear music and birds and the rain, filled me with inexplicable gratitude. Everything seemed more beautiful than ever before, more alive. I paid attention to things more and more. I found a new appreciation for myself, for my body, that allowed me to see, hear, smell, taste and touch. I was falling in love with life, with myself and with humanity in ways I never thought possible. Life was different and I was different. I loved my long skinny legs that I once was so ashamed of, even with the scars. I remember sitting on the shower floor, wrapping my arms around my legs and kissing my thighs and knees, my heart bursting with appreciation for them; something I had never previously felt. I have never told anyone because it sounded stupid and ridiculous that I did that, but I did that. I kissed my legs because they were beautiful and I was thankful that they were mine. For the first time in my life I loved who I was and the body that housed me.

IN THE EARLY YEARS

I remember coming in and out of consciousness, and through my daze I heard them speaking. They said that if I survived I would be a vegetable. I couldn't understand what they meant and wondered what type of vegetable, and would I be tasty? I started thinking of my mother's cabbage stew, and then heard them say that my life wouldn't be worth living. It all came back to me; I was in a car crash and it was serious. That

was 21 years ago. The journey since then has been a rollercoaster ride with heart-wrenching drops, exhilarating loops, ominous tunnels through dark mountainsides and everything in between.

I wondered, what was I meant to learn from all of this? It had to be terribly important because this experience that I was going through was life-altering, deep stuff, on so many levels. I had just started to embrace myself. I had finally come to terms with and appreciated the things about me that I thought were unlovable. I reached a place of spiritual awakening. And then everything changed. Did I really have to go through the test all over again? It felt like a test. How accepting of myself was I really, especially now, with a body that was unacceptable to many and perhaps even repulsive to some. In *Embodying the monster: Encounters with the vulnerable self*, Margrit Shildrick (2002) argues that bodies viewed as “disabled” are monstrous and that our reactions to them are ambivalent. I did not understand just how much the non-disabled norm informed my identity, and the vulnerabilities that would surface as a result of acquiring a physical disability.

Recovering from the physical injury was a long and tedious process. Recovering from the emotional and psychological trauma was in many instances more difficult and, in fact, masked, until symptoms of depression emerged. In the early years, my husband had been my only support. I felt lucky that I had someone who loved and cared for me the way he did and was often reminded by others how lucky I was. This reinforced the belief that people with physical disabilities do not have the luxury of being wanted, adored or loved, not only because of the burden they impose on others, but because of their bodily difference. Secretly, I was relieved that I was not single and did not have to go through the hassle of dating and hoping someone would find me worthy. I did not have to prove anything to anyone. When my husband left me, everything that I feared became my reality. For the first time since the accident I felt the full weight of my disability as there was no longer someone else to share the “burden” with. I had come face to face with my insecurities. I was not enough. I was not whole. I was a broken person. Only this time I could not hide the scars with make-up or clothes; they were there for the world to see.

Yet, going through the experience of awakening before the accident had in some way laid a healthy foundation for my emotional state. Even though I had reached the lowest point in my life, I understood that I had a lot of work to do and that rebuilding myself had to start with me. I had already started the journey of self-love and acceptance, so it was

simply a matter of remembering and doing it again. But this proved extremely difficult, it was not like climbing back on a bike and riding. I recognised my own physical difference in terms of not having an able body and the set of limited physical abilities I had to work with. From that point on I only had myself to depend on, which was the real test. All the external stuff was gone; no more frills, nothing fake.

The internal dialogue was deep-rooted and relentless. Who was I—as a mother, as a partner, as a friend, and as a contributor to society? Who was I as a woman? My biggest fear after the breakup was that I would be alone, and that nobody would want to be with me, a divorced mother of two with a physical disability, let alone find me attractive. I knew that the non-disabled norm was what was valued and glorified socioculturally, because it is whole and is the standard which we aim to attain. My fears were very often validated by people closest to me. For example, a close family member was deciding what to wear to a wedding that we were both invited to. As we were talking, she stated without thinking, “at least you don’t have to worry about what you would be wearing!” After realising what she had said, she then added, “Oh, you know what I mean!” It hit home because it was the truth. Why did I even bother? What was the use when, even though I understood that I would get everyone’s attention because everyone notices the wheelchair, nobody would really *see* me. Was it only the external aspect of a person that held any value? Was it only the physical body and the clothes that adorned it? But why was that so important, and what about my essence as a person? Did that not count?

The body of an able-bodied person was what I had to strive to attain. If that was not achievable then I would try to live a life as close to what it was before disability. I started working again, which contributed to my financial independence. I became even more independent when I started to drive. I had a circle of friends, an active social life, had interesting hobbies and even dedicated time to charity. Yet, although my life had a semblance of normality, I was still reminded that my outward appearance wasn’t what it should be. I was told to sit up straight; posture was indicative of confidence, as was the firm handshake—both of which I struggled to do as a quadriplegic. I had my own sense of style and felt most comfortable in jeans and t-shirts, never dresses, because I did not like to show off my legs. But I was often encouraged to wear sexier clothes and make-up, and to show my feminine side. When I did this, I was praised in a way that said, “See, if you do this you can be ‘more’ feminine, woman, sexy”.

My hair was my crowning glory—thick, dark, long and lovely. It highlighted the feminine aspects of me which was perhaps lacking in other areas. I once again learned that my outward appearance, and how I was groomed, was important if I wanted to be accepted and acknowledged. It was also important to look my best if I wanted to attract a partner.

I experienced many difficulties in expressing my own uniqueness within a system designed for people without disability. I had to articulate a new way of imagining my body whilst at the same time blurring the boundaries. I did this by illustrating alternative representations of disability in a way that subtly defies the stereotypes of disability as asexual. By blurring the boundaries of what was generally accepted as feminine, I tried to create a notion of fluidity (Image 3.2).

A fluid notion of the body to me was one that questioned the dichotomy of perfect/imperfect or able-bodied/disabled.

This was also the time when I felt comfortable within myself to start dating again. From this point on, when I was in relationships, I never felt inadequate. I recognised my own physical difference in terms of not having an able body, and having a certain set of physical limitations, and this did not seem to matter. I felt loved and adored, just as I was prior to my disability. My partners were all non-disabled and I never felt the lesser partner or that I was lacking in any way. When the relationships ended it was never as a result of my disability, unlike my marriage. Being in these new relationships has been a huge contributor towards my feelings of self-worth and validation as a woman. I was accepted by others in the most intimate way and felt that I was loved for who I was as a person as a whole. The relationships that I had built with family, friends, lovers, colleagues had in a sense validated me as a person of value. I had come to realise my own ability within my disability.

Over the years I had worked hard at achieving a relatively “normal” life. Who was I trying to be ‘normal’ for, I wondered? Was it for my friends so that I could fit into the mould of acceptability? Was it for my partners? Was it for myself? When something has value, it is because it is compared to something better or worse than itself. I realised that using others as a benchmark or mirror of how I should feel or look would only serve to make me feel inadequate and inferior. Why allow myself to be assessed by any norm which excludes me? The only way I could change this was to change the object of comparison, from someone else, to myself. In order to face myself and the essence of who I was as a person, I had to strip off all the frills and fluff. And so I did. One of the ways I did



Image 3.2 Reflection (Photo by Amin Arnold Gray)

this was to cut off all my hair. It was extremely liberating as my hair was part of the external which bound me to conform. In order to embrace myself completely, my value could no longer be dependent on others' opinions and acceptance of me. And for that to happen I had to come to the understanding that I was different, and it was okay to be different.

I can't always express my femininity in traditional ways, but that's okay. I no longer need to conform. I no longer need long hair. I can be myself and feel comfortable in my skin and in what I choose to cover my skin

with. I am unique, my body is not perfect; but what is acceptable and what is a perfect body? So now, I wear dresses and shorts when I want to because I can. My quadriplegic legs are perfect. I have short, natural, unruly curls because that is how my hair is. It is perfect. I am a woman without having to be groomed in frills and bows and heels in pink, and I don't need to adapt to society's standards of femininity in order to show my femininity.

I now look at life with even more awe as I embrace the wonder of being able to see a perfect sunset, smell cinnamon, hear Satie, feel the sun against my skin and eat delicious food. But more than being humbled by my experiences, I love who I am and the body that houses me in all its imperfections.

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