

Jala's Story:

Jala wrote her own story.

The Disability

I am 24 years old and have lived with Cerebral Palsy (CP) since complications at birth. The form of Cerebral Palsy I live with, Spastic Quadriplegia, affects the muscle tone and motor coordination in all four of my limbs and core, along with my balance. These physical impairments have meant that navigating through a large majority of everyday living tasks does not come without complications. I will not deny that ever since my dramatic entry into the world - three months premature and weighing only one kilogram - confronting and finding approaches to overcome hurdles has at times been both challenging and energy consuming. However, I endeavour not to expend too much time dwelling upon the hardships as my disability has also made achieving goals all the more rewarding.

I suppose you could say I perceive my CP as a unique opportunity to appreciate the small pleasures in life that may otherwise go unnoticed. For example, for as long as I can remember I have always gained thorough enjoyment from swimming. For a large proportion of able-bodied individuals, developing a breaststroke technique is probably not a massive milestone, but it was an especially pertinent achievement for me considering I was initially advised that my physical limitations meant it likely I would never progress beyond floating and sculling on my back. In fact, my mum and I share a longstanding private joke that my name may mean "*Bride of the Sea*" in Arabic but to us I am "*Bride of the Pool*". I may not be the fastest but I sure do have the heart for it.

Family Support

While my extended family live interstate and overseas I am very grateful to maintain strong, close bonds with members of my immediate family. This is so true that we, and our two loving dogs, all still live together in the same childhood home we have had since I was six months old. I am proud to be the daughter of a kind, hardworking couple who later this year will celebrate their 30th Wedding Anniversary together. I am the younger sister of an intelligent, witty young man with a loyal and generous heart and the granddaughter of a strong and courageous woman. Having me for a daughter, sister and granddaughter hasn't always been easy or without sacrifice, and as such, I want my story to reflect their importance in my journey. After all, it is in part

the consistency and relentlessness of their love and support in correspondence with that of my friends that has made it possible for me to live as close to my potential as I have. My family and friends, along with a broad array of medical professionals and therapists in both insignificant and monumental moments of my life have helped me identify the best version of myself. They have supported me as I continue striving towards becoming that person. Of course *my life is* still a work in progress!

Volunteer Work

As I reflect upon the milestones and different seasons my life has passed through, one of the features that resonates most prominently is that anything I have undertaken, whatever direction my life has gone has required undeterred commitment and hard work. At the same time however, these events have also offered me opportunities to make connections with some truly special people. Take my younger days as a Charity Ambassador for example; the responsibility of portraying the numerous Associations' messages and worthwhile contributions was at times stressful for me as someone who is intrinsically a humble person.

Nonetheless, it was also a wonderful platform for giving back, paying it forward as a voice for other children also living with disability and in doing so interacting with some highly inspiring families and professionals. While I have experienced funding deficiencies and lengthy waiting lists as a recipient of children's equipment services, over these years I did also establish rewarding relationships with therapists and other people living with disability.

In relation to recreational pastimes, I had endured multiple failed attempts at a varied collection of hobbies before I found the Australian Youth Choir. This venture wasn't without its share of physical accessibility problems but it did allow me to source more than three years of friendship.

Multilevel Surgery as Part of my Journey

Another potent experience surrounded my multilevel surgery. For those of you for whom multilevel is an unheard of concept, it is where a series of orthopaedic procedures are conducted in the one sitting. In my case the operation went for the duration of six hours. This orthopaedic process asked of me a three month absence from school and another 18 months of daily rehabilitation but also brought me one of my most cherished and enduring friendships in my life to date. My initial years at high-school were marked by bullying, isolation and loneliness but I endured this and went on to secure high enough grades for acceptance into my first preference at

University. Along the way I discovered a friend with whom I still enjoy regular communication.

The Experience of University

My course at university is an undergraduate double Bachelor's degree in Social Work and Social Planning. My motivation for entering this domain encompasses the notion that I strive to work with, and alongside, people who take the time and effort to acknowledge human capacity. I possess strong passion for supporting those who are experiencing stress, and aspire to aid them in discovering who they are and who they want, and can, be if and when they have access to appropriate resources and support. The physical logistics of mobilizing around the Flinders campus in addition to managing to balance the academic workload was daunting to start with and has been a challenge over the years. However, a disability access plan where I can utilise extra time, a stenographer for exams and be assessed through oral presentation format if need be, has helped make success possible. So much so that in the summer of 2007/2008 I was awarded acceptance into the Golden Key International Honour Society, for the top 15 per cent of students across all disciplines in the Flinders charter for that year.

Following the acquisition of the first 18 months of my university course full-time, a recurring illness flared up again and required surgery, this consolidated my plan to scale back to part-time, but my fluctuating health meant this was not enough to alleviate the stress. I held hope that taking a break from theoretical study by undertaking my first professional field placement would be the special ingredient that would reinvigorate my health once and for all. I met some lovely people who are wonderful professionals and was provided with the opportunity to rehearse a selection of worthwhile practice skills. This related especially to the development, organisation and running of Advisory Groups. Regrettably however, through it all my health was still failing me.

Surviving and Recovering from a Medical Crisis

Until this point my life had not detoured too greatly from the one I had envisaged and planned for myself. This was all about to change however, when last year I was faced with an extremely rare and life-threatening medical crisis. With only a three month gap between, I spent five months of last year receiving treatment in two Hospitals. I have never appreciated the combined interplay of all my protective

factors and the many wise words of advice I had been given over the years more than during this, my lowest ebb to date. My health was looking rather precarious for a while but the journey started to improve when my family and friends reminded me of how much I had to live for, who I was and most importantly who I could be again. I was still me, even if I had to approach things slightly differently and look after and pace myself better.

In a radio interview as a nine year old child I once said that courage is about having the hope to never give up and making the best of what you have got, your resources and abilities. This is definitely a mindset I needed to enforce more than ever. A medical professional I hold in high regard once told me to “*Always remember where you started from*” I have learnt that nothing in life is ever going to be a perfect fit for me, it is up to me to mould it and make it work. Another of my favourite maxims is to never look down upon someone unless it is with the intent of helping them back up again. I acknowledge this is the approach adopted by the second hospital responsible for my care. Rather than focussing solely on my physical impairments, they treated me with dignity, compassion, patience and gentle encouragement and recognised me for my talents. I will forever be thankful for that and have now witnessed firsthand the positive outcome this approach can produce.

My Goal

The true meaning of success for me will be when I can become someone who in both my personal and professional identities treats others with conduct and practices that align with this philosophy. If the events of last year taught me anything it is to take nothing in life for granted and sometimes the best laid plans are not the ones we are meant to follow. Nonetheless, for now I am resuming my studies with the confidence that whatever I end up undertaking, helping people will be at the cornerstone.

Enabling Factors

This event process is by no means a critical incident that I would want others to ever experience but has been fundamental in highlighting the things in life I place greatest value upon. First, is the prime importance of family and friends, it is they who can make all the difference in positively influencing your mental wellbeing. Second, are the benefits of maintaining yourself as functionally mobile as possible, to the best of your ability. My fitness endurance was most advantageous in propelling me toward near full recovery. Thirdly, but not least of all, education which will provide me the

foundation to emulate the professionals I have met. I am no one extraordinary but I hope sharing my triumphs and trials will encourage you to keep pursuing your own pathways. You are special and your situation unique but you are not alone.