

Teenage Adventure Camps Queensland Speech. By Oliver Collins, 2018

Living with a progressive disability is a bit like planning an amazing trip to Italy with friends, and on the way there you get separated and you end up in Holland. You had read all the guide books about Italy, and made all these plans to see the Coliseum, to visit amazing places like Florence and Venice and Milan, to eat endless amounts of pasta and pizza and cheese and drink amazing wines while hanging out with your friends.

At first, you're devastated. *Why didn't anybody else get lost too?* You might ask. *Why am I different to all of my friends?* And one of the scariest thoughts you might have, *is there any single other person on the planet who knows what happened to me? Who knows and understands what I'm going through?*

Holland is a very scary place when you think you're on your own. You haven't read or seen much about it, you've never talked with your friends about wanting to go there, you haven't been given any time at all to prepare, and they eat this weird raw, fermented fish thing which smells gross!

Imagine, just for a second, how that would feel. Being excluded from the trip your friends are going on. Seeing all their posts on Facebook about how much fun they're all having together, all the photos of the places you could've gone, meals you could've eaten, and things you could have done. Knowing that while they are all on the same journey together, they won't be able to know what it's like for you.

It takes you some time but eventually you feel it's time to get out and see where you've landed. You soon realise that, whilst it seemed scary because you thought you were on your own, there are actually other people who've ended up in Holland too. They may not be going through exactly the same things as you, but they can understand. It's not the journey you expected to have, nor with the people you expected to share it with, but it is nevertheless an incredible journey. Beautiful at times and challenging at times; hilarious at times and devastating at times. This is your journey.

That is a nice little metaphor, based on Emily Perl Kingsley's reflection, 'Welcome to Holland'

Hello everyone, and thank you for having me here today. My name is Ollie, and I have a condition called Fibrodysplasia Ossificans Progressiva, or FOP for short. There are only 15 people in Australia with my condition, and about 800 around the world. It is a condition which causes my muscles, tendons and ligaments to turn to bone, gradually encasing the body in a second skeleton and eventually totally restricting all movements. As yet, there is no known cure, and all potential treatments that patients are undergoing at the moment are experimental at best.

It's hard to describe what it's like living with a condition like FOP. To go to sleep every night, wondering if you may wake up tomorrow and not be able to do something you've done every single day of your life, something as simple as reaching for a glass of water. To worry that every time you fall, or get the flu, or push yourself physically just a little too hard, that that could cause a huge flareup and limit the rest of your life. To think that one day, you may very well no longer be able to walk, or cut your own food, or brush your teeth. I experienced this for the first time when I was 12 years old, when I woke up one morning and could no longer lift my arm above shoulder height. Since then it has been a slow but definite decline and now I'm left with very limited movement, particularly of my upper arms. This is the case for many of the very

special people who attend the Teenage Adventure Camps Queensland, or TACQ. Some of them face conditions much worse than FOP, and have ended up totally dependent on others to do almost everything for them. Others, like me, are still somewhat able – but heavily reliant on others to help them in managing many of our normal everyday tasks.

It's not until you've lost something that you truly appreciate how important it is. We all take these seemingly, very simple tasks for granted. Even me. Even though I have had to come to terms with the fact that one day, I may not be able to do them. When all my friends are going out into the world; more independent than ever before, going on overseas trips for months at a time, driving a car, living out of home; I find myself struggling with the idea of separating my dependence on other people to help me with everyday tasks from my becoming an independent self-sufficient adult. While for many people, their parents involvement in the bathroom stops when they're 5 years old and can bathe themselves, for me I was given a tantalising few years of showering independence before they were back, and I needed their help again to wash my hair, as for the last 13 years I haven't been able to touch my forehead, let alone shampoo my whole head. For many of the TACQ campers, this is the harsh reality.

This is equally tough on the parents, as well as the campers. There is the difficulty of balancing the independence of their mindsets with the dependence of their bodies. I know we have had many arguments, or as mum likes to call them calm and orderly family discussions, in our house because we are all struggling with the balance between my physical needs and my needs as an adult in making my own decisions and living my own life. In families such as mine, this is made even more difficult by the fact that, because parents have not been able to given up their caregiving roles from a physical perspective, they struggle from an emotional perspective to let go of their child. This is why camps such as TACQ are so important.

I was lucky enough to be offered a spot in this camp for the first time in 2008, when I was 14 years old. Back then, I was much more cute and innocent. I was still being a goody two shoes, doing almost everything my parents said and asked, following all the rules. This camp seemed very intimidating to me at first, going away with a group of strangers I had never met. What finally made me commit was when my older brother, Will, agreed to come along as my carer. Back then, I didn't need as much help. But I had never had anybody other than family helping me, and the thought of having a stranger help me in

the shower or pull up my pants freaked me out. Will knew this. I'll always remember that fateful Sunday, being picked up by the maxi taxi to drive down here to Currumbin. Little could I have known what an incredible impact those 7 days would have had. This was one of my first big experiences with other disabled teens in Australia EVER, and it was, to put it simply, amazing. We went jetboating, we went in helicopters, we terrorised a golf course full of people racing around in golf buggies, we went to see the Draculas show, which at 14 seemed highly inappropriate and rebellious. I did things I never would have been able to do with mum and dad, and most of all, because of the environment created by Dave and the TACQ team, you feel comfortable enough and, whilst at times a little risky, you feel safe enough to give everything a go. That's the most important thing, and something that young people with disabilities often do not get to experience. You can't face a choice to do something if you're never given the option to choose. At TACQ, you get to make the decisions.

For many of the campers, this is a very big deal. A lot of them, in my experience, had been very sheltered and coddled their whole lives, wrapped up in cotton wool by overly concerned parents who were too scared to take any chances. And this is something we can all understand. As much as having a

disability can sometimes be terrifying, it would be even more terrifying for parents of children with disabilities looking on, dealing with the constant unknown. They are all just doing the best they can to cope. That's another reason why this camp is so important. Not only does it give parents a much needed respite, it helps show them that things are possible. That just because their children might be limited in one way, does not mean they have to be limited in the dreams they have and what they want to do and hope to achieve with their lives. Also, and I think this is a very important thing that is often forgotten, people need to be reminded that having a disability doesn't mean you can't have fun, and take some calculated risks. Whilst the TACQ team is very conscious of peoples' disabilities, that is not the focus. This camp helps people forget, even for a short while, the everyday struggles they face because of their limitations. For some, this is the only holiday they're realistically able to take their whole year, and so this is the thing they look forward to most.

Attending this camp helped me appreciate the silver linings that you can find from having a disability. As politically incorrect as it sounds, and much to my parents' despair, I have become very adept at playing the cripple card. When we go to the nightclub at 2am, and the line to get in goes around the corner, my amazing friends assume 'carer' status, and I limp up to the bouncer with a

pained look on my face, and inevitably we're whisked straight through the door. Lord knows what they think when I'm still there, several hours later, dancing away; but it works every time. My friends also love that I can get happy hour extended by an extra twenty minutes because I "couldn't walk up to the bar fast enough". My parents have always encouraged me to look for the positives in all situations. Although I'm sure this is not what they were really referring to, living my life with an attitude like this has been invaluable in helping me learn to accept myself and realise all the things I am capable of.

Its not all fun and games though. My parents have always instilled the values of hard work in me, and my brother and sister. They have also been very firm in letting me know that just because I had a disability, does not mean I am excused from working hard and doing well at school, in order to go to university and then get into the workforce. I was lucky enough that my parents sent me to a very good school, Gregory Terrace. With the support at that school, both academically and from the disability services team, I was able to excel at school and finish with a high enough grade to get into law school at the University of Queensland. After 6 years of study, I graduated at the end of 2016 with a bachelor of law and commerce. After graduation, I started working in the dispute resolution, or commercial litigation, team at King & Wood

Mallesons, a top tier law firm in the Brisbane CBD. Since then, I have graduated from my diploma of practical legal training and was admitted to the Queensland Supreme Court as a solicitor in October last year. Working at a top tier law firm has been a huge adjustment from my days at university. While a full time law degree is two or two and a half days a week, plus some study at home (and probably not as much study as I should've done according to my parents) working full-time is a whole different ballgame. I will often have 14-16 hour days, 3, 4 or 5 days a week. There is a lot of pressure, as we are working for large commercial clients, in large-scale legal disputes. There has been a huge physical and mental demand, which I have never experienced before. The TACQ camps I attended helped to inspire me though. They helped to give me the drive to show other, able-bodied people what people with disabilities are capable of. I know not every person with a disability is capable of holding down a fulltime job, let alone one as demanding as this one. But I feel I owe it to the people I met on that camp to prove to the world that, whilst we are differently abled, we are still capable of doing things that we put our minds to, if we are passionate enough. That is not necessarily limited to working full-time, as it could be things like driving a car, like Tom Latcham – a camper a few years ahead of me, or moving out of home, like some of the other people with disabilities I've met, like my friend Sara. Everybody has things on their bucket

lists; I know I certainly still do. Attending a camp like this has helped give me the strength and persistence and show me the true value, of doing everything you can to reach your goals and accomplish everything you want in life.

Its hard trying to raise awareness for disability. People can't really empathise unless they've gone through it themselves or with someone very close to them like a parent or sibling. And of course, you wouldn't wish this experience on anybody. But try to imagine ending up in Holland. Try to imagine watching on while all your friends enjoy Italy and you're stuck in Holland, feeling very isolated. And imagine how special it would be once you realise that there are other people who ended up in Holland too. That's why we need TACQ.

The harsh reality is that, with our ageing population, almost all of us will, in some way, be affected by disability. Believe me when I tell you that, if you're able to donate your hard earned money in support of this amazing cause, it will make an incredible difference in the lives of everyone who is lucky enough to be able to attend the camps.

Helping support initiatives like this, helping those who are unlucky enough to face disability from a very early stage in their lives, is so important because people with disabilities need to realise that we are special. We do have something very important to say, and something meaningful to contribute to society. TACQ helps give us the voice and strength to do it. Thank you