

# Consider This

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First published: December 2012

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To my family.

## Prologue - Two Casts

Showtime.

From the wings of the stage, I watched Roger stroll out and sit on one of the downstage tables, idly tuning his guitar. That was my cue. I took a deep breath and stepped onstage, taking my position front and center. I paused to give the ensemble time to come on from the wings behind me. Together, we looked out at the audience, who looked expectantly back at us. The house lights of the theater were still up, and I scanned the crowd, picking out my parents, who beamed up at me from the third row.

I was standing in the center of a delicately organized detritus, the stage set up to reflect an edgy East Village loft. The two downstage tables were covered in cables, music fliers, and general clutter. Having the entire cast onstage for the opening added a sense of both claustrophobia and urgency to the show's fledgling beginnings. I couldn't wait for the explosion of energy that burst from the stage when the entire cast became one in the roar of the opening number.

I glanced over, making sure my camcorder prop, which had been a toy gun in an earlier life, was in position, facing me on a tripod. It accompanied me everywhere in the show, a silent witness to the "last year on Earth" that formed the backbone of the show's plot. I'd always loved taking photographs and writing, so having to play the part of a compulsive documenter was definitely something I could do.

I always loved that first moment when you stepped out onstage. The thrill of being transformed into an actual performer, a player who "struts and frets" his hour upon the stage, was exhilarating and liberating. I was no longer Tommy, I was a documentary filmmaker, a grumpy florist, or a nameless gangster in the Al Capone era. Theater represented limitless possibilities to step out and break away from everyday life and become part of something transcendent.

The lead-up to a show is always nerve-wracking, but the second I hopped onto that stage, that was it: all the rehearsals were behind me, and there was nothing left to

do but enjoy performing the show. I pointed my “camcorder” towards me, faced the audience, and addressed them directly as I launched into my opening monologue.

*December 24th, 9pm*

*Eastern Standard Time*

*From here on in, I shoot without a script*

*Let's see if anything comes of it — instead of my old shit.*

Except that it wasn't Christmastime. This was April 25, 2010, and I was starring in a local youth production of “RENT”, playing Mark, the geeky narrator.

As I spoke those words, my character setting the scene and reminiscing on the year gone by with his friends in New York City, I myself thought back over the last few months, reflecting on how much work it'd taken me to get this far. Just over two months before, my right knee had been injected with steroids and the leg had been put in a cast for six weeks.

The specialist in Dublin had done this in an attempt to relieve my knee pain, a chronic problem caused by my underlying cerebral palsy (CP). At the time, I thought being in a cast was the end of my chances of appearing in a production of RENT, but here I was.

My opening monologue gave way to some dialogue, and then we threw ourselves into the opening number, a biting cynicism look at a real life “getting more like fiction each day”. Still, though, I found myself on autopilot, my thoughts far outside our small theater, thinking back to the day of my audition in February 2010 is the unshakable feeling of being distinctly out of place. Quite apart from being limited to stiff, awkward movements thanks to knee pain and the cast, I was also the youngest there, and I didn't know anybody. Everybody around me greeted each other as friends, having worked together numerous times before. I was the new kid, foolishly hoping that he could get the role of Mark. Not for the first time, I wondered if all of this wasn't a mistake.

While I had been in the cast, I'd been sleeping terribly and been on a lot of painkillers, although my knee pain had steadily diminished. I had to be in the cast for six weeks, starting mid-February. If I got the part, I'd be spending most of rehearsals in the cast, even though I'd be out of it for the show itself. While you're in a cast, the

muscles of your leg begin to atrophy, becoming weaker due to lack of use, and so it would take a lot of strengthening to get them back to normal. In this way, RENT served as a big motivation for me — I had to be up and running (literally, in one scene) by April 25.

Audition day started with the whole group of us singing the show's main chorus number, "Seasons of Love". I wasn't overly familiar with the song, which started with simple piano chords ascending and descending mesmerizingly. Our rehearsal pianist, Eoin, played the song's opening a couple of times, letting us get used to its straightforward melody, and then we started singing, our voices plaintive and meek.

*Five hundred twenty—five thousand  
Six hundred minutes,  
Five hundred twenty—five thousand  
Moments so dear.  
Five hundred twenty—five thousand  
Six hundred minutes,  
How do you measure, measure a year?*

I thought about those words. They seemed fitting. I'd always been a ferocious documenter, forever taking photos or writing blogposts, desperately trying never to forget a moment, a feeling, or an event. We repeated that a couple of times, gaining confidence with each try. The harmonies were simple enough, and we soon introduced them, our voices interweaving through its powerfully simple verses. The second verse suggested how life could be measured out; in daylights, sunsets, midnights, and cups of coffee.

I thought back to what I knew about the song, one of the show's only chorus numbers. It opened the second act, and although it ostensibly took place at a funeral, it was very much a song of joy and celebration. I liked the song a lot.

Singing in a group connects you with those people in a way that's very hard to replicate. Despite being the youngest and least experienced, I felt part of this group for the first time that day as I sung.

We finished the song, and individual auditions began. I'd never really done an individual audition before, so I had no idea what to expect. I didn't think the fact that I was awkwardly leaning on crutches was making it any easier. This was a show where dancing on tables was kind of a prerequisite; what was I doing here? At least I knew the pianist.

Eoin was a few years older than me, and while we weren't hugely close, we got on quite well. I've always maintained that the best teachers are those who absolutely love what they teach, and it was obvious that Eoin adored music.

"So, what are we doing today?" he asked, his easy smile dissipating at least some of my nervousness.

"Uh, What You Own", I told him. It was my favorite song of the show, a driving duet with Roger near the end of the second act with powerful electric guitar riffs and pounding drums. Its long phrases and harmonies were among my favorites of any song, ever.

Eoin's face fell, which deflated some of his infectious energy. "I don't think I know that one", he said, frowning at his songbook and flicking through the pages, his manic energy still present.

Inwardly, I began to panic. Should I have prepared another song? Why was I singing a duet, anyway? Tentatively, experimentally, Eoin began playing the opening chords, and I threw caution to the wind as I dived into the lyrics. "What You Own" comes at a time of the show where Mark wonders if he's not totally out of his depth. I could empathize.

*You're living in America,  
At the end of the millennium,  
You're living in America,  
Where it's like the Twilight Zone.*

When we reached that familiar chorus, I began to relax a bit, easing into the song a bit more and actually starting to enjoy singing it. Better still, Eoin stuck his head out over the top of the piano. "Oh, I do know this one!"

When my chorus ended and Roger's began, I faltered, unsure how to continue. The vocal director, a motherly figure whom I adored, filled in for his part. Together, we reached the end of the song much faster than I would have expected. Did auditions always end so quickly...? As I thanked them and left, feeling an adrenaline rush like none other, I smothered fears that I'd fumbled or made a mistake. No, there was no reason to think I'd screwed anything up.

Despite my youth and inexperience, I ended up getting the part of Mark, and was nothing short of euphoric. I loved this show, this cast, this experience, and I threw myself into the rehearsals, finding them to be as tiring as the exercises I did to regain strength in my knee. From “La Vie Boheme”, a funky love-song to all thing bohemian, to the haunting soliloquy “Hallowe’en”, I gave the show my all and watched with pride as it came together. Despite not knowing any of them well before, I became incredibly close to the cast — we truly felt like a family. In the end, the injections and the cast didn't cure my knee pain in the long run, but performing RENT remains one of the happiest experiences of my life.

This vignette (I affectionately refer to it as “the time of two casts”) is a good example of when something I was passionate about was in direct contention with my disability. I wanted to do this show, but at the same time, my knee pain was interfering with simple, everyday activities like going to school. It's often the case that people with disabilities will have something that they dearly want to do, and they have to figure out how to do it within the constraints of their disability. This is a human story; a story of overcoming difficulties.

This is my story.



## **Chapter One - “The Early Years: Open Your Left Hand, Please”.**

Writing about my early years has been tough in places. I only remember flashes of this, and have had to construct the rest from photos, videos, and talking to friends, families, and physios. Much of this chapter is based on the recollections of my parents, Lily and Denis. To say that I owe them a debt of gratitude would be to allow a grievous understatement go unchecked. They made me who I am today, and a day doesn't go by that I don't feel incredibly grateful for that.

I was born in 1994, after a relatively uneventful pregnancy. From the day after I was born, though, I cried almost continuously for three months. My mum thought that my cries had an unusual pitch, and worried that something was wrong. In the hospital, she asked the pediatrician about it, but her concern was dismissed. The crying was later attributed to colic (abdominal pain caused by wind or obstruction) and I was prescribed medication. After three months, I finally settled down and my parents were able to relax.

Over the months that followed, I was slow to develop. My parents weren't overly perturbed, because the doctors had reassured them that the crying was due to colic and I'd settled down. Plus, I was their third child, and so by this stage, they were experienced parents who accepted the fact that children develop at their own rate. It wasn't until my routine 12 month developmental check that I was termed “developmentally delayed”. They got the diagnosis of cerebral palsy (CP) when I was 18 months.

CP is defined as a disorder of movement caused by brain damage before or around the time of birth or during a child's early years. Technically, CP is not a progressive condition, as the brain damage does not get better or worse beyond the initial damage. In reality, though, it does cause knock-on effects, such as muscle tightness and poor posture, which in turn cause problems if left untreated. For this reason, ‘treating’ cerebral palsy is geared more towards limiting the knock-on effects rather than curing it, and is achieved through physiotherapy and other treatments, including surgery. My exact diagnosis is spastic diplegia, the most common form of CP.

When a child with spastic diplegia is born, the brain is the only part of the body that's damaged — the muscles and bones are not. As most children grow, muscle growth is proportionate to bone growth. As a child with spastic diplegia grows, however, their

muscle growth doesn't keep up with the bone growth. This leads to knees, hips, and other joints becoming flexed, which makes it difficult for the child to stand up straight. Weak muscles, joints pulled out of position, and poor balance lead to difficulty walking. Once adulthood is reached and bone growth ceases, the challenge of muscle growth keeping up with bone growth is removed.

Treating a child with CP involves stretching tight muscles, strengthening weak muscles, and trying to get the child to move with normal patterns of movement. This includes trying to get the child walking as soon as possible, both to promote normal musculoskeletal development and for social reasons. Walking is such a normal childhood activity, it's incredibly important that, if the child is to have as normal a school experience as possible, that they are no further behind the development of their peers than is absolutely necessary.

From being worried about me for the first 3 months to being at ease for the 9 months that followed, it came as quite a shock to my parents to learn at 12 months that I was developmentally delayed, and to have my CP confirmed at 18 months. That diagnosis galvanized them into action; they began learning about CP and devising program of exercises with the help of physios — they felt that they owed it to me to do everything within their power to support me reaching my potential. They proceeded to follow a tough daily program of muscle stretching and strengthening with me, introduced and monitored by physiotherapists both local and in the Central Remedial Clinic in Dublin.

My early years were defined by this aggressive program of exercises. If my parents hadn't done the program early on, a lot of irreversible damage would've been done to my body — this wasn't something that they could have started when I was, say, 12. They told me later that it was tough to watch a very small child doing such an intensive program, but I'm thankful they did.

Mum told me how difficult it was to try and cajole a toddler into doing the exercise program. Thinking back, I remember doing them, and how we all tried our best to make them “normal”, and to integrate them into our normal family routine. Every Saturday, Dad did the stretches on me. I'd need some form of entertainment to keep me occupied or distracted, so sometimes the TV was on. It was around this time that I fell in love with audiobooks, raiding the local library and turning it upside-down for new

things to listen to. Dad would listen with me, and together we listened our way through C.S. Lewis's *The Chronicles of Narnia*. Other times, John would read us something, and even to this day, I remember much of Hugh Montgomery's *The Voyage of the Arctic Tern*, even though I doubt John or Dad do. I stayed listening to audiobooks long after stretches, though, and to this day, they're the main way I consume books.

What was sometimes tough about the exercise program was the fact that to the physios, I was just a child, but to my parents, I was their son. As well as being parents, they had to assume the role of therapists at home, and felt bad that a small child had to endure such a tough regime of exercises. At the end of the day, they believed it was in my interests, and so they persevered.

Doing the program was undoubtably an arduous experience, because it was long and intensive. The same exercises had to be done day after day. You couldn't see results every day, but we were rewarded when I achieved breakthroughs, like being able to do something I hadn't been able to before. Such breakthroughs could be as simple as being able to lift my leg higher than I could previously, but sometimes, they were much bigger:

Mum and Dad, even before they married, were incredibly fit and active people; both of them had finished marathons and triathlons before they were married. They were huge fans of cycling, and my dad in particular had a deep desire for me to be able to go on trips with them. Cycling had been a huge source of joy for them over the years (they spent their honeymoon cycling around Cyprus and their 25th wedding anniversary cycling the length of France, a journey of some 1,000 miles) and they dearly wanted to share their love with me as they had with John and Patrick, my older brothers. It wasn't easy, though, and Dad often wondered if he was pushing me too hard when he had to nurse a wailing toddler who'd just taken a tumble off his bike. These were rewarding moments, though. In Sligo in 2002, Dad took the stabilizers off my bike for the first time. Mum wrote later what happened: "While he couldn't get on or off the bike by himself, Tommy was very excited and cycled round and round in circles, shouting 'Tell me I'm not dreaming!'"

Before I came along, my parents didn't have much of experience with disability; Mum's background was in science and Dad's in engineering. The first time it was mentioned, they didn't have the faintest idea what cerebral palsy was. Over the months and years that followed, though, Mum read everything she could about CP, learning

about bones and muscle groups in an attempt to gain a better understanding of my condition. She felt she couldn't do an exercise or a treatment without first understanding it. The knowledge she gathered over the years led her to do a Masters in CP in 2007.

Mum often drew parallels between the exercise program of a disabled person with the training program of an athlete. While I had less choice in following the program than an athlete would, the two aren't entirely dissimilar. We both need a body of lean muscles and require a healthy diet; we both have "coaches", although mine is a physiotherapist. Another similarity is that neither program is forever — athletes retire, and once I was fully grown, I'd need a much smaller program to just stay flexible and fit. While an athlete is aiming to win competitions, my aim is to be able to lead as ordinary a life as possible.

My therapy was a big workload in a house that was already busy, with two self-employed parents and two older siblings. While carrying out my program, Mum gave up working for a few years in order to devote herself to my care full-time. There was a significant cost associated with this, but my parents were willing to take it on for my sake; they firmly believed that the needs of their child came first.

Despite all they did for me over the years, Mum and Dad always wanted to dispel the notion that they were especially great parents, as they didn't see themselves as anything like that; they were nothing more than ordinary parents who tried hard for their son. That may be true, but I am who I am today because my parents thought that they could make a difference. Looking back on it, I'm reminded of a quote from "Think Different", a 1997 advertisement from Apple: "The people who are crazy enough to think they can change the world are the ones who do". My parents may not have changed the world, but they changed mine. They believed in themselves enough to think they could change my life, and for that, I'm grateful.

My parents trying to do their best for me wasn't always easy. When I was about 15 months old, a pediatrician who'd just seen a CAT scan of my brain told Mum that he was very concerned about the amount of brain damage present and the effects it would have. His overall tone seemed to insinuate that there was very little brain there and that I'd probably never be able to lead an independent life. Mum felt that this prognosis didn't match the lively, alert baby she knew and so she disregarded this opinion, but it showed

how my parents' perseverance and willingness to do anything for me was not always matched with encouragement or optimism from professionals. After that meeting, Mum called Dad in floods of tears, wondering if she could do it at all.

A few months after my diagnosis, an uncle of mine told Mum about the PETO Institute, a center in Hungary which specialized in conductive education as a treatment of cerebral palsy. In early 1996, a few months before my second birthday, the whole family traveled to Budapest by car. We stayed in Hungary for three weeks, where I attended therapy, and Mum and Dad learned more about the institute's approach to treating CP. Even though I was very young, I still have vague memories of traveling to Budapest that spring and attending the institute. I remember it being an incredibly regimented experience, a big difference from working with my parents.

Conductive education is a system that has been developed specifically for people with motor disorders of neurological origin, such as CP. It looks at the child's needs as a whole and aims to reach goals that are not limited to motor function — they also aim to give the child greater independence and fine motor skills while developing their communication abilities. Teachers of conductive education are known as conductors, and they assume the role of physiotherapist, speech therapist, and occupational therapist. The PETO Institute described conductors as 'motivators' who set realistic goals for people with motor disorders.

In summer 1996, a neighboring family had organized for a PETO Institute conductor to come to Ireland to treat their child. They asked us if we wanted to share the conductor's time and thus the cost in having one come over to Ireland. Mum was delighted and accepted the offer. I met the conductor, Szilvia Czibok, and the two of us worked very well together over the next few years. Her first trip to Ireland was for three weeks, and it worked out so well that Mum and Dad organized for her to come over routinely for three weeks at a time. This continued from 1996 to 1998, from when I was aged 2 until 4. With Szilvia, I began to make progress: I began walking with tripod crutches before progressing to two walking sticks. From there, I began using just a single walking stick before starting to walk independently around the age of 3. I progressed from parallel bars to rope bars and being able to lean down and pick things up from the floor, which would require me to balance on my own for a few seconds. Overall, working

with Szilvia constantly moved me on in terms of what I could physically achieve, building muscle strength and improving my balance.

While studies haven't shown that conductive education is more successful than conventional therapy, I'm in no doubt that it's a better system in a lot of ways. It provided a skilled person who could come to my home and do an intensive daily program with me, which wasn't available with conventional therapy.

Szilvia made numerous videos of the work we did, so Mum and Dad could continue doing the exercises with me when Szilvia went back to Hungary. I had never looked at the videos before beginning to write this book almost 16 years later. Without having to look at them, though, I had clear memories of that time — even though the work was hard, we treated the exercises like a game and on the whole, I look back on that period with a definite fondness. It's clear from videos that the exercises were tough and took a lot of energy out of me. She was an excellent therapist, even when I was less than cooperative. When I watch the videos, I never saw her get angry at me, although she did mockingly threaten to go home once or twice (which would always make me obey the command immediately, showing the bond we forged).

In places, the videos she took seem to be little more than a series of short commands —stand, wait, straighten, open your left hand, please— given in a very straightforward manner. In one video, I'm standing at a rope handrail in front of a mirror, practising lifting my knee enough to step sideways. I'm obviously tired: my movements are slow and labored, and several of the exercises leave me panting. "Where's Mum?" I whine. At one stage, a noise can be heard off-camera, in another room. Onscreen, I realize that John, Patrick, and Clodagh (a family friend who would go on to become my babysitter and later study physiotherapy in college), have come home. This distracts me, and Szilvia has to repeat her next command several times before I obey it. In the next scene, I'm at a table, making a picture with colored sheets of paper and glue. I have obvious difficulty managing the stick of glue, holding it, claw-like, and clumsily knocking it over at one stage.

As well as affecting my right leg, CP also affects my left hand. It's not entirely useless, but it can't do much. I spent a long time looking for ways to make my life easier, at least partially circumventing the effects of the CP in my hand. In 2010, I changed my

laptop keyboard to the Dvorak key positions, as opposed to the almost universally-accepted Qwerty layout. On my laptop, the keys are now mixed up, the vowels having moved to the left center row and the commonly used consonants (T, S, R, and so on) grouped beside them. Having the keyboard laid out like this is touted to be more ergonomic, although so far, I haven't seen definite evidence supporting Dvorak's superiority in this regard (which is something of a running joke in the online tech community). What I do know, though, is that the right hand does more work when using the Dvorak layout rather than Qwerty, which means my weak left hand does less work, and I can type faster.

As I'm gluing things together, I reach for a marker. "Dis is de owange", I say, more to myself than anyone else. As I watch the videos some 15 years later, I sometimes have trouble making out what I'm trying to say onscreen. In other parts, I can't fathom what I'm trying to say at all, and Mum has to translate what I'm saying for me. When, on the video, I sing "Row, Row, Row Your Boat", the lyrics are almost indecipherable. While I do have memories of working with Szilvia, watching these clips in 2012 is unusual for me, since it's hard for me to see the little child onscreen as me. My movements are a lot more awkward and ungainly, and I struggle much more with everyday objects and tasks.

In several of the scenes, there's music playing in the background. Mostly, it's classical, but once or twice, I recognize some children's music. When I watch these videos, I vaguely recognize Spring, from Vivaldi's Four Seasons, and wonder if this was where I first got into classical music.

Szilvia also made up little songs to help me do certain tasks, which she'd sing as she corrected my balance or got me to practise a particular skill:

*I am standing,*

*I am standing,*

*I am standing tall.*

She made up most of the melody lines herself, but sometimes, she'd take an existing song and change the lyrics to make them applicable to me. She would sing

another song, to the tune of “The Bear Went Over the Mountain”, when I practised walking with good posture.

*Tommy went over the mountain,  
Tommy went over the mountain,  
Tommy went over the mountain,  
To see what he could see.*

As well as making videos, Szilvia also took many pictures, keeping them in albums that I still have to this day. They document the period from July 1996 to March 1997, as I learned to walk independently, just coming up to my 3rd birthday. The first photo was taken in our kitchen, with me standing with Mum. “Truly clever, I’m with my Mum. I try to stand with her” reads the inscription. In the photo itself, I’m half turned towards the camera, a tired grin on my face. In another, dated January 1997, I’m grinning a toothy grin and clutching two yellow tripod crutches, which I’d named Pongo and Perdy after the two main canines in Disney’s “One Hundred and One Dalmatians”. The caption underneath this one reads, “I have two friends besides the rope: Pongo and Perdy. They follow me everywhere!”

In the years since she worked on that intensive program with me, Szilvia and I have kept in touch, She invited the family to her wedding in Hungary in 1998, and I visited her when she was living in London. She’s also visited Ireland with her family. I had lunch with her in Budapest in August 2012 while I was writing this book, and was immediately reminded how well we got on. She showed me some drawings of mine that she’d kept, as well as some homemade cards from John and Patrick that they’d given her to welcome her to Ireland each time she came. This again brought home to me just how much the intensive stretching program had felt like a game for most of the time. I thought of Szilvia as a friend, someone whose visits I looked forward to rather than dreaded.

From an early age, I also attended physiotherapy both locally and in the Central Remedial Clinic (CRC), which provides medical and educational services for people with disabilities. We started attending the clinic from when I was just over a year old, and have continued going every couple of months in the intervening 17 years. Looking back



on those visits, they still feel like days out to me. Most of the time, I went with Mum; we would drive up, attend the appointment, and go for lunch somewhere. Even though it was, say, a physiotherapy appointment, I saw it as a day off school and it never bothered me too much. Over the years, the main service I needed was physiotherapy, as my main problems were musculoskeletal, although, as a child, my speech was also delayed and so I attended speech therapy. (These days, as I do the Leaving Cert., gushing over everything from the economic theory of comparative advantage to the belligerent naval policy of Kaiser Wilhelm II, I'm sure there are lots of people who wish I didn't talk their ear off quite so often.)

When you're going to physiotherapy, it's largely up to you, the patient, whether these appointments are to be suffered through or treated as days out. They're never what you'd call "fun", but for me, they weren't too much of a chore. I was a fairly sociable child, and I got on well with the physios. Treating them as friends rather than taskmasters helped me cope with the fact that I didn't have a whole lot of choice about doing the exercises, and I think the feeling was mutual — when I was presenting a project in the Young Scientist competition on children with CP in mainstream school, my physio was the one of first people to visit me at the exhibition.

One day, when I was very young, I was chatting to Mum and asked her who'd she pick if she learned that the world were ending and she could only save 10 people, assuming her immediate family were safe. She started naming some of her family and some of Dad's. When she asked me the same question, she thought I'd start naming family too, probably starting with Robert, a cousin I was particularly fond of. Instead, the first people I named were "Carmel and the two Anns". (Carmel Murray was our local physiotherapist; the two Anns were Ann Kennedy, a CRC physiotherapist, and Ann Jenkinson, who worked in the CRC's gait lab.) I think that story shows how patients, parents, and professionals could not only work as a team, but even actively care about each other too.

While I was doing all the physiotherapy program, I was growing up as well, and getting to the stage where I was taking responsibility for my treatment. When I was very young, Mum and Dad chose to do the exercise regime and, because I was only a toddler, I did it. When I got to the age of 6 or 7, and certainly by the time I was 9 and the first surgery in the US came around, I had started taking charge of my CP. I think that Mum

had always intended that I'd get to the stage where I was solely responsible for keeping fit and flexible and going to appointments and so on; even in the early years, she'd would always make sure that I knew what all the exercises were and what each one did, preparing me for the day when I'd be doing them myself. I think it's important that, where possible, parents of children with disabilities should impart that responsibility to their children so that they can go on into adulthood being able to manage their own disability.

Mum and Dad noticed that I was musical fairly early on, and asked if I'd like to learn an instrument. Both John and Patrick did violin, and so I tried that first. I enjoyed trying to learn, but struggled with the intricate finger-work required of the left hand. The teacher waited for us to say that it wasn't working it before saying so herself, and we deeply appreciated her understanding and patience. That attitude was never guaranteed, though, and we saw the other end of the spectrum too. After the violin, I tried piano and went to the same teacher that John did. Towards the end of my first term, I was abruptly dismissed because, in her words, "He's got a very weak left hand. Piano music comes for two hands, and I need the time to prepare other children for exams". Mum was understandably astonished at her attitude, but it ultimately taught her a valuable lesson: success at certain things is very dependent on meeting the right people. If my Mum hadn't looked for and found another, nicer teacher, I wouldn't have had several happy years playing piano. I immediately clicked with this new teacher, and Mum did some research, discovering that keyboard music is mostly comprised of right-hand work, which leaves the left to focus on simple chords. As I was going through a phase of loving James Bond movies, Mum bought me a songbook of 007 movie theme-tunes arranged for the keyboard. Ask me to play the opening of Goldfinger sometime, it's a great tune.

It's very easy to think of a damaged brain and get disheartened, thinking of all the things that you'll never do because you have cerebral palsy. I'll never be able to be a professional footballer, but if 99.9% of the population can't for one reason or another, is that still a big loss? I mightn't be able to become a pilot either, but there are hundreds of reasons that people can't become pilots, of which CP is only one. The fact that cerebral palsy limits what you can do is undeniable — but it's far from the only limitation in life.

People with disabilities can (and do) go on to lead rich, full, engaging lives

despite their difficulties, in the same way that non-disabled people lead rich, full, engaging lives despite what difficulties exist in their lives.

## **Chapter Two - First Surgery: 'Birthday Syndrome'**

While I was growing up and doing intensive rounds of exercises, Mum was learning everything she could about CP. She came across a world-renowned surgeon, Dr. Jim Gage, who specialized in treating CP at Gillette Children's Speciality Healthcare in Minnesota, America. When it was deemed that I needed surgery, we met with Dr. Gage in 2003, and after a preliminary examination, he said that I would benefit from surgery and we settled on a date in March 2004.

Dr. Gage divided problems stemming from CP into three main categories. Primary problems are caused by injuries to the brain around the time of birth. These problems are static: they do not improve or deteriorate further. They do, however, lead to secondary problems, where muscles become tight and pull bones into the wrong positions. Finally, tertiary problems are problems resulting from the child's attempts to cope with the primary and secondary problems. Surgical intervention mainly deals with secondary problems. Dr. Gage had been one of the early surgeons who'd developed single-event, multi-level surgery over the alternative: "birthday syndrome", which was the common approach during the 60s and 70s. The phrase, coined by Dr. Mercer Rang, referred to the method of treatment where ambulatory children with CP would typically have one surgery to correct one secondary problem (such as lengthening of the hamstrings, which are muscles at the back of the upper leg), which would be followed by a year of intensive rehab, followed by another surgery (such as an Achilles tendon lengthening, in the heel) the next year, which would again be followed by another year of intensive rehab. This process, an operation every year, and physiotherapy all year around, would go on yearly throughout children's growth years. Single-event, multi-level surgery, on the other hand, carried out all of these procedures —and others— in one large operation, with just one period of rehab afterwards. Dr. Gage has written extensively on the subject.

This surgery, when I was 9, was to set me up for the period of rapid growth that happens around the time that a child becomes a teenager, and make sure that I developed as well as I possibly could. It was hoped and expected that most of my secondary problems would be solved, and that this would give me as efficient a walk as I could achieve. The surgery consisted of some 16 procedures, which included:

breaking the femur (thigh bone) and rotating it, lengthening the hamstrings, adductor muscles of the hip, and Achilles tendon performing a derotation of the tibia (shin bone), moving it into a more correct alignment, moving the position of the rectus femoris muscle (one of the four quadriceps), constructing arches in my feet, which had previously been flat.

All of this aimed to give me a more energy-efficient walk. When a gait pattern deviates from the norm, it causes more strain on joints and muscles, and requires more energy to be used in walking. A surgeon once equated the amount of energy needed for a child with CP to walk with the amount that a normal child required to go up stairs. In essence, children with CP go from place to place expending the same amount of energy as though they were constantly walking up stairs.

To be honest, I didn't have a clue what to expect when I agreed to undergo the surgery. Before it, Dad and I were interviewed for Mum's masters (assessing outcomes in single-event, multi-level surgery) in order to get an understanding of the patient's and the parent's expectations. When I was asked about my aspirations for the surgery, I simply said:

“[I] just want to be able to walk straight and walk faster”.

Dad hoped that the surgery would improve my endurance and might allow me to do things like go cycling with them. He also talked of how the surgery was another example of my determination, but to me, it wasn't so much courage as pragmatism, and my thought processes revolved around the same core logic. Firstly, developmentally, I was worse off than normal. Secondly, there was something (surgery, for example) which could improve how I function. Therefore, in my mind at least, it was a foregone conclusion: I would always go along with something that would ultimately benefit me, no matter how much pain or discomfort it initially caused. How could I not?

It's for this reason I've always been uncomfortable with people who told me that I was brave or that I inspired them — I feel like I don't deserve their praise, as I was just doing it. Over the years, even before I fully understood my situation, I recognized the

fact that my parents were trying to do everything they could to give me as full a life as possible, and so I trusted them implicitly. When discussing the prospect of surgery, in the car going up to Sligo with Mum one time, her assurance that it would ultimately be beneficial was all I needed to agree to it. Even when I got to the hospital itself, I wasn't nervous about it all. As Dad mentioned in the post-operative interviews:

“Dr. Gage came into see Tommy before [the surgery] to ask if he was ready and if he had any questions. Tommy's only question was something in relation to the color of the teddy bear [the nurses would give him] afterwards... he was totally unconcerned with the activity happening around him”.

Most of all, I think that Dad hoped that the improved energy would allow me to go distances without having to use the wheelchair, and hoped the surgery would help me to cycle with the family. I didn't have a lot of concerns regarding the surgery, preferring not to dwell on whether or not there'd be pain or discomfort. Dad, at the time of the pre—operative interviews, explained how my lack of concern was his main concern about the surgery:

“My only concern is that Tommy has almost too lighthearted an approach to the surgery. I feel that after the surgery, he'll be hit like a bombshell in that he'll suddenly realize that he's totally incapacitated and in some pain”

He did admit, though, that a lack of concern was preferable to fear, though:

“I'd hate to have him suffering going into surgery as well as suffering coming out”.

I don't think it was a case of me not having concerns — I think I just managed to compartmentalize and then ignore them.

My aspiration for the surgery, to “walk straighter and walk faster”, is representative of how I viewed the difficulties of my condition as a whole. Physiotherapists are primarily interested in things like a muscle's range of motion —

that the norm is, say, 125 degrees of flexion, and the patient only manages 115 degrees. Whether or not I had that 10 degrees of flexion never bothered me, but sometimes, that reduced movement would affect me in my everyday life, and then I absolutely cared about it. When I was younger, I'd struggle to bend my leg up in front of me so that I could put on a pair of socks. That bothered me, and I had to find a different way. Additionally, one of the improvements after the surgery was better balance. I don't know how charts showed this, but I noticed it immediately the first time I went to carry a cup of coffee from the kitchen table to the sofa and was able to do so without spilling the coffee. In this regard, I think that physiotherapists would do well to focus on the practical implications of disability. I can't speak for other people, but they're certainly what I focussed on, and I think it'd be a safe bet to assume others do too.

When we went to the US in March 2004, it was just after France expressed strong opposition to America's invasion of Iraq the previous year. Because of this, French hotels in America had discounted rates due to the decline in business, and we stayed in Sofitel, a French hotel in Bloomington, a town 20 miles southwest of St. Paul. Since we were staying for about five weeks, we soon got to know the staff there. In particular, the concierges became friends with us. One day in the middle of our stay, one of the concierges, Raki, gave me "Brum", a remote-control car. Hotel guests soon grew accustomed to seeing a small child with a shock of red hair controlling a noisy yellow toy car from his reclining wheelchair. I still have the car, and as I write this eight-and-a-half years later, its headlamp eyes look down at me from the top of the wardrobe.

In the brochures that Gillette Hospital distribute on how to emotionally deal with surgery, the importance of distractions while dealing with pain is mentioned. This was especially relevant for me because, after the epidural came out on the day before I was discharged, I took no other pain medication. I was used to Calpol, a sickly-sweet liquid pain medication, that I sometimes took back home, and I refused to take anything else. With regard to distractions, I watched a lot of James Bond movies and read a lot of books in the weeks after surgery. Dad read the "His Dark Materials" trilogy to me, and would sometimes sing to me if I woke up in pain in the middle of the night. Although I didn't recognize it at the time, I deeply appreciate the fact that my parents never tried to force me to take medication, even though it was a rougher time for them because of it.

Additionally, it's lucky that we were staying in Bloomington, recognized nationally for the United States' second-largest shopping center, Mall of America. We went there many, many, times during our 5 week stay — I was never much of a shopper, but it was a completely different environment that allowed me to relax away from our claustrophobic hotel room. Malls are fun places, with lots of bright lights and shiny things to distract a 9-year-old from his pain. I spent many happy hours there with “Brum”, the remote-control car. It was very funny to watch people's reactions when they first encountered the car; often, it would almost trip them up, but when they turned around in annoyance and saw a child in a reclining wheelchair controlling it, they'd never fail to break out into a grin. Well, almost never — my remote-control shenanigans were cut short one day when a mall security guard picked up the car, approached my wheelchair, and told me and Dad that it was causing health-and-safety concerns.

I was admitted for surgery on March 23, 2004, which was estimated to take 6 hours. Two teams of surgeons worked on me, working on each leg independently. The teams worked on the individual procedures that required me to be on my back first, before turning me on my front and completing the remaining ones.

Following the surgery, I began an intense period of rehab, the likes of which I'd never experienced before. I think I underestimated just how immobile I'd be, and just how much discomfort that would cause. Because of all the work that'd been done on the hip (inserting metal pins and lengthening muscles), it could barely be moved during the healing process, which lasted three weeks. Towards the end of the four-night hospital stay, I had a number of physiotherapy appointments, and Mum and Dad were given a range of passive stretches to do, which had to be done at least three times a day. Weight-bearing, getting me back on my feet and walking, couldn't be initiated until X-Rays confirmed that the realignments had been successful and that bones were healing well. We got that green light, though, and I was introduced to a reverse walker so that I could begin active stretching. Gentle hip stretches were also started. Because I had surgery on multiple joints, I was initially unable to maintain correct alignment while walking or standing, and knee immobilizing devices were used to give additional support and allow me to control only the hip joint. I returned home on April 30, 2004.

In May 2004, I continued the stretching and strengthening program that the hospital had given me. Gait re-education continued using parallel bars and a reverse



walker. I went back to school for a two-hour period each day and resumed swimming, which had long been my favorite form of physical exercise. I was also seen by a local physio twice a week. In June, I progressed from the walker to two crutches. I was recovered enough by July to go on a camping holiday, where the stretching and strengthening regime continued. At this point, we were concentrating on the quality of my walk and the distance I could manage. By August, I could stand unaided but still used the crutches to walk. The following September, I resumed school full-time and now walked independently, and reduced my physio visits to just one a week. I met Dr. Gage again in Oswestry, Wales, in November 2004. He was very pleased with my progress and was confident that further gains could be made, especially once the plates that had been inserted into my hip and knee during surgery were removed. These were removed in Dublin in January 2005.

While the professionals in Ireland were excellent and very caring, the systems and facilities weren't as good as those in America. For example, surgery in the US was confirmed many months in advance, while surgery in Dublin was only confirmed the evening before. In Ireland, confirmation came at 5pm the night before the scheduled date that a bed and nurses were available for surgery to proceed the following day. This meant that we had to get organized and set off for Dublin, two-and-a-half-hours away, on what was a cold and wet January evening. My mum had to deal with family logistics as we went to Dublin, but I also had to rapidly prepare myself emotionally for another surgery. (Going into hospital for surgery was never a pleasant experience, and as much as I tried not to complain at the time, I hated, hated, having to go through everything.)

In Dublin, I had to be brought in the night before surgery in order to be prepped for surgery, which included ensuring that I was fasting from midnight. In the US, bringing children in on the morning of major surgery was the norm, with parents being responsible for overseeing such preparations. For a six-hour single-event, multi-level surgery in the US, I stayed in hospital for four nights, which was a night longer than normal. (This was due to my inability to take oral painkillers.) For a simple twenty-minute plate removal procedure, I stayed four nights in hospital, the minimum stay that the hospital required after that procedure.

One of the main aims of the surgery was to eliminate my crouched gait. By November 2005, whilst there had been a big improvement in my crouch, my left knee

was still flexed at the point of my right heel hitting the floor. I also still had a moderate Trendelenburg — my body dipping to compensate for the weak right hip abductor muscles. In addition to all of the stretches, strengthening, and physio appointments, I also had to keep up with the activities of a normal 10-year-old, which was making me exhausted. My parents decided to take me out of school in March 2005 so that I could focus on the final rehabilitation. I'd repeat the school year in September to compensate for the fact that I'd missed large chunks of both that year and the one before it. In July 2005, I was walking well and deemed to be completely recovered (16 months after the American surgery). I still continued an exercise program, which included swimming and using a treadmill and stationary bike as well as passive stretches of the hamstrings and other muscles.

The 2004 surgery drastically improved my gait, but it was a big shock to my system. Having said that, I think I was able to cope with smaller issues as they cropped up since they were much easier than single-event, multi-level surgery. For the next few years, I focussed on academics rather than physiotherapy, starting secondary school three years later. I still kept up fitness and flexibility, but adjusting to new experiences was what occupied me the most.

## Chapter Three - Blogging: Trust Tommy

*“A blog is, in many ways, a continuing conversation.”*

*Andrew Sullivan*

I'd always found that I loved writing. When I was younger, I would write short, two-page stories. As I grew up, had surgery, and started secondary school, I continued writing stories in my spare time. It was what I did to relax, or when I was bored. When doing homework, I'd rush through my other subjects until I got to my English homework, where I happily threw myself into essays or any sort of functional writing. As blogging (online diary keeping) began to rise in popularity, it seemed to be a perfect fit for me: an outlet for me to write; a place to practise and, hopefully, improve. All I needed was an introduction, because, at the time at least, blogging didn't feature high on an Irish teen's radar.

That introduction came when Patrick left for college in autumn of 2006. He set up a blog for me and asked if I'd keep it updated on what the family were up to so that he could read it in the US. When I was starting out, I found it hard to do. I felt as if there wasn't much to write about. I went to school, did bookish things from 9-3, and then came home. There really wasn't any way I could make eating a plate of spaghetti bolognese interesting. I got more and more sluggish about updating the blog, until I gave up entirely a few months later. In early 2008, I decided to try again. I created a new blog, and decided that this was my blog, and I wouldn't write it with any sort of slant. I wrote it for myself.

For the most part, the blog was a day-to-day synopsis of what I got up to. I guessed that it wouldn't be of interest to anybody who didn't know me (and probably some people who did, too), but that didn't really bother me. I just enjoyed having an outlet to write. Here's an excerpt from September 12, 2008:

Tomorrow will see me heading into town to buy a copy of *By Royal Command* by Charlie Higson. Also known as *Young Bond VI*. It is (as you may have guessed) the fifth

installment of the Young Bond series dealing with James Bond's childhood. Should be good.

I gave the link to friends and family, and the blog took on a much more conversational tone, where I'd often poke fun at the fact that I knew my parents would be watching it. I once ended a blogpost I'd worked on for a couple of hours on with:

"(And as far as my mother is concerned, this is a scheduled entry and I'm not actually awake at 1am in the morning.)"

Because it was thanks to Patrick that I had started blogging, and my parents read my blog as a matter of course, I never found myself in dangerous territory regarding revealing personal information online:

"Okay, on the one hand, you know that I was at the zoo last Saturday, or that I'll be at a wedding on Thursday – I'd have no problem saying something like that. Is there a problem with that? It's not embarrassing for me, the zoo isn't some... I dunno, gentleman's interest club (or if it is, I missed it) so it's not like the zoo is something you wouldn't want your wife to know about."

Even though my parents were quite lenient about what I wrote about online, I was aware that not all parents were the same, and took care not to reveal personal information about others:

"You might notice that I never really go into some details about school. Yes, I had double Business on Friday, but what'd I do at break? I intentionally never talk about my friends and, no, that isn't because I have none, which has been suggested, but merely because they mightn't be as comfortable to be mentioned on the web, and that's fine."

Nowadays, I write about pretty much anything — tech news, what music I'm listening to, where I'm traveling to, or just generally what I'm up to. I loved the idea of documenting my life and being able to go back years later to read what sort of person I'd

been. While I was writing this book in August 2012, I could go back to September 2010 and see how I coped with surgery. The blogposts showed me where I'd gone, the exercises I'd done, the restaurants I'd eaten and the milestones I'd reached.

When I started blogging, I also began to meet other bloggers, some of whom were disabled and who shared their experiences with disability very candidly on their own blogs. I followed suit, writing about my experiences with CP and how it affected me. When I started secondary school, I wrote a lot about I was adjusting to busier corridors and more walking to get to different classes. Those other bloggers showed me that there's a lot of benefit to talking openly about disability. Too often, I think, there's a sense that people shouldn't talk about their shortcomings and impairments, especially given that the internet gives people the opportunity to put forward their best sides and not talk about other facets of their personalities. Blogging for so long has taught me that you absolutely cannot judge a person's personality from what they write online — everybody's playing a part, even if it's partially based on themselves.

I came to realize that writing openly about my struggles with disability was not only cathartic to me (long before blogging, writing about problems had been my way of solving them), but other people —who I'd never met and only knew me from what I wrote online— appreciated my posts on CP too. Some were grateful that someone with firsthand experience was talking about their disability, while others who didn't have CP but appreciated the insight into what it was like to live with a disability. Some even joked that I should go into politics. In my experience, people with disabilities can be split into two camps — those who dwell on what they've lost because of their impairments, and those who still flourish despite them, and my blog was always a chronicle of someone who never let their disability get in the way of a full life, and I think that made an impact on people. Readers of the blog started e-mailing me, thanking me for giving them a better understanding of what a disability's like:

Hi Tommy, enjoyed your blog, [...] It gives me heart that you are so full of enthusiasm for life. I know that a life can be enjoyed no matter what the handicap. [...] Thanks for sharing your intimate thoughts.

Sometimes, these e-mails would come from the family or friends of someone with cerebral palsy:

[Your blog] gives me so much hope to think that my grandson could have a 'normal' life that includes his CP. [...] We are all determined that he will be helped to reach his potential, be a happy fulfilled person. I think you will be a wonderful role model for him.

I appreciated those e-mails, and it's indescribably heartening to think that what I was doing, simply writing a diary of my thoughts and experiences, was making a difference in someone else's life, in the same way that other disabled bloggers had made a difference in mine but that was never the primary reason I wrote about CP.

In 2008, I started using a cane. It was called Aislinn, which was an in-joke born on a friend's blog. It was to help me balance and alleviate some of the pressure on my knee, but mostly, I was using it for social reasons. With 1200 students, those corridors would often be quite packed and because I had poor balance, there was a risk that someone would accidentally knock into me and I'd fall. With the cane, jostling became less of a problem because people saw me and gave me a lot more room. Previously, I'd shied away from using a cane because I didn't want to be different. Now, though, when the suggestion came up at a physio appointment, other bloggers with disabilities talked to me and I realized that, not only was it worth it, but it was okay if it made me a little different from others. I wrote about it on Trust Tommy at the end of the school year, after I'd been using it for a few months:

"It's a physical manifestation of my disability. People see Aislinn, and they stop, they let me through doors, they make room for me, they give me more time if I'm following them somewhere. When I was younger, I hated this. People were always instilling this need to conform. 'We're gonna make you as normal as everyone else', they'd say. I was young, and so I went along. I squeezed through those gaps, I ran a few steps to keep up with people. Except, now I'm older. I'm beginning to think 'I don't want to be the same'. I'm obviously not. Inside, I am, sure, but being the same as everyone

else doesn't really help the fact my muscles are weaker than normal. If all the cane does for me is help me socially, then by god I'm sticking with it."

Blogging also had a couple of other advantages, although these weren't immediately apparent to me. For one, I got to practise writing, which both improved the quality of what I wrote and was an enjoyable use of my time. Since 2008, I've written over a thousand blogposts. Even though I was mainly writing for my own sake, the blog's enjoyed a not-insubstantial number of readers and has won two awards at the Irish Blog Awards; best newcomer in 2009 and best youth blog in 2010. While it was undeniably an honor to win those, the real value of blogging from my perspective was the fact that I got to talk to a lot of people whom I otherwise wouldn't have met. Some of these people were bloggers who also had CP and who made me a lot more comfortable with my own disability, while others worked in professions I was interested in and offered me internships. Some of them were just people I called friends.

During two summers in 2010 and 2011, I also took an unpaid internship with Adrian Weckler in the Sunday Business Post, whom I knew only from Twitter. There, I got a taste of what it was like to be a real journalist — researching stories, conducting interviews, and writing copy. As I wrote on Trust Tommy:

I think the best way of summing up why the last two weeks rocked is that I didn't feel like an intern. I wasn't just making tea or doing research for other people's articles. I was writing my own articles, doing my own research and conducting my own interviews. One of the others would suggest an article and I'd have to decide what best angle to approach it from, and who'd be the best people to talk to. As I wrote it, Adrian or Dick would have a read over it and offer advice as to how to improve it. 'It sounds better if you do this, rather than that' or 'House style is "15 per cent", not "15%"'

To say that I learnt a lot about journalism would be a gross understatement. You can read books or webpages, you can talk to real journalists, but going into their place of work and doing what they do is nothing short of sublime. Every student should do work experience at some stage. I'd say most offices wouldn't mind taking an unpaid intern on in some capacity. Plus, how can someone choose a college course or a career based on no experience? Why should they have to?"

In 2011, I worked with Niall Harbison at Simply Zesty, a social media blog. I got to learn about video production and social media, writing articles on a wide spectrum of tech issues. As I later summed up:

“Working with Simply Zesty has given me experience in working an office, certainly, but it’s not like any office I’ve worked in before. Other offices don’t have a cat that happily prowls around the desks, for one thing. It’s a lovely place to work, though, which I’ll miss when I finish on Friday.”

Out of everything I’ve done in the last few years, it’s blogging that’s probably shaped who I am the most, because of the experiences I’ve had and the people I’ve met. It’s made me a better writer, and someone much more comfortable with their CP than they once were. I’m also a lot more independent and confident. I worked in the Sunday Business Post when I was just 15 — I had to take on a fair amount of responsibility for my work, and deal with a lot of adults I didn’t know, which isn’t always easy for any teenager. In an environment like that, you either manage it fine or you quit. Luckily, I stuck with it, and learned a lot while I was there.



## **Chapter Four - Secondary School: “So, what happened to you?”**

When I started secondary school in 2008, I was a year older than my classmates, because I’d repeated a year of primary school after my first surgery in 2004. I think that this had a tangible impact; I sometimes found it hard to get along with the younger students. I’d moved schools the same year that I repeated, and I had a hard time adjusting. This was mostly because I’d reached the age of being self-conscious of the CP, and I was faced with the prospects of the other kids’ scrutiny and questions. I could either get over my nervousness and self-consciousness and make friends with the other kids, or I could remain reserved and avoid awkward conversations. 11-year-old me chose the latter option, which meant that I spent the rest of primary school distant from other kids, but I wouldn’t go as far as I say that I was actively unhappy. That said, I don’t look back on my years of primary school with any particular fondness.

I went into secondary school with a certain apprehension. I was still self-conscious, but the larger student population made me wonder if I wouldn’t be the only disabled kid there. Also, it was about this time that I began blogging and interacting with other people who had disabilities, and who made me a lot more comfortable with my own disability. All in all, I looked forward to starting secondary school: it was a step forward, and hopefully a step up. To cap it all, I’d have John close-by again, which was comforting.

There was a good bit of adjusting to do. More people meant that corridors were busier, and I sometimes struggled to get from one class to another with all the (somewhat inevitable) jostling that happened. I came up with ways of coping, and for the most part, I didn’t have serious problems.

In January 2010, I decided to enter the Young Scientist Exhibition. Both Patrick and John had entered before me, and I was eager to experience it first-hand as an entrant. I did my project as a study, aiming to find out what issues children with CP came across in mainstream education. The result was far from a representative study — I received just 11 responses through St. Gabriel’s Center, an organization based in Limerick which provides services to children and young adults with physical disabilities. What the study lacked in statistical credibility, though, it made up for in its usefulness to me: it taught me a lot about what to expect in secondary school, and reassured me that

children with CP led near-normal lives. It wasn't even the responses that did so — doing the project as a whole required me to look closely at what attending a mainstream school entailed for someone with CP. I'd always found it easier to skirt around my CP rather than talk about it directly, and doing that study provided a springboard for me to talk about my concerns, veiled in the context of the project.

I was delighted to win the first prize in my category (social and behavioral sciences), but I also given a bursary for winning 'overall best communicator' at the exhibition. Given how my speech was late to develop and that I spent a year in speech therapy, this meant a lot to me.

Secondary school served as an illustration of obvious versus imperceptible effects of a physical disability. Ambulatory children with CP usually walk with an 'obvious' impairment. What isn't obvious to the casual observer is the 'knock-on' effect of that obvious impairment, such as the tiredness an inefficient walk can cause. Tiredness is not an obvious disability: you can't see it in the same way you can see the impaired walk. While CP is defined as a disorder of movement caused by brain and nerve damage, most of the major problems faced by children with CP, highlighted in my Young Scientist project, were 'knock-on' effects of CP rather than the disability itself.

Sure enough, secondary school often left me extremely tired in the evenings. I was working on schoolwork and also trying to have as normal a school experience as possible. I played to my strengths rather than trying to do things I knew I couldn't — I dropped PE and spent the time studying, reading, or working on debates. I'd joined the school debating team at the first opportunity, and I participated in a number of debates during the first three years of secondary school, mixing facts and statistics with playfully argumentative rhetoric and (sometimes fictional) personal anecdotes. The memories of school debating stand out as some of the happiest memories of secondary school for me.

Debating definitely increased my self—confidence, but more importantly, it was a lot of fun. For the most part, the motions were straightforward enough and allowed mixing facts and statistics with quasi-argumentative rhetoric. We debated such motions as “The Irish do too much drinking and too little thinking” and “Commercialism is taking the joy out of sports”. During the former, my brother Patrick was held up as an example of an Irishman who thought rather than drank in the speech directly before mine. In the 30-second gap before my speech, I rewrote the latter half of my argument

to rebut the assertion that thinking and drinking were mutually exclusive. During the latter, I had a lot of fun using personal anecdotes to argue my point — there was nothing I enjoyed more than a group of my friends and I getting together and watching a match together, I said. It didn't matter whether anecdotes were true or not (this particular one wasn't: I'd probably have trouble knowing which way to hold a hurley, and I very rarely watched sports on TV) as long as they illustrated and backed up your argument. I think that public speaking's an incredibly useful skill to have; I often argued (using debating skills!) that it should be a school subject, since it's a skill that'd get a lot of use in adult life.

I did Music as a subject for my Junior Cert., and there's a practical part of the exam, where the student has to perform 4 pieces. The marks from that are added to the written and aural section of the exam to get an overall grade. I'd become a fan of singing early on; performing the Beatles' "Norwegian Wood" is a party piece I do with my Dad. I'd also done some musical theater with CenterStage, a drama company in Limerick. When the time came to decide what to do for the practical aspect, I knew that I'd sing for at least some of it.

Since I had to do four pieces, I decided to sing two and perform two on drums, which were the other musical love of my life. I sang "Losing My Religion", one of my all-time favorite songs, and the eponymous hit from "Sunset Boulevard". I thought it was a good idea to mix the genre of songs, and was happy to settle on a 90s alternative rock song and something from musical theater.

I'd been doing musical theater for a couple of years at this stage, but I much preferred singing to acting; I wasn't a particularly good actor, but I had an okay voice, and had often wondered how to separate the two so I could focus on what I really loved. This seemed like a great opportunity.

When I went into the music room, the tables had been pushed against the walls and a microphone set up beside the piano. I introduced myself and shook hands with the woman who was grading the practical exams, a music teacher from another school.

"So what're you singing?"

"Losing My Religion. R.E.M." I said, putting my sheet music on the stand, trying not to let my knee shake too much.

"Oh, great tune, great tune" she said. I grinned, feeling a little more confident.

I positioned myself in front of the microphone and adjusted the music stand so that my words were level with my eyes. I took a deep, steadying breath, and gave my music teacher the nod.

She pounded out the opening chords emphatically, and the last of my nervousness disappeared. The opening chords of "Losing My Religion" were probably my favorite of any song — instantly recognizable, simple, and, best of all, upbeat. I nodded my head in time with the beat, and then launched into the words.

*Life is bigger  
It's bigger than you  
And you are not me  
The lengths that I will go to  
The distance in your eyes  
Oh no, I've said too much  
I set it up*

At this stage, I was pretty much on autopilot. All my worries about forgetting the lyrics had been unfounded; my subconscious took over and I didn't have to look at the sheet once. Honestly, I'm never happier than when I'm in the middle of a song. It's a heady, intoxicating experience: you hear nothing but the piano and the words, which don't feel to be coming from you — at least, you're not doing anything consciously to produce them; it's as if they're coming from somewhere external, outside your own consciousness, and yet your mouth is making those sounds, enunciating those words.

"Consider this" I sang, flinging my arms out to my sides. I splayed my hands out, feeling the energy of the song coursing through me.

*Consider this  
The hint of the century  
Consider this  
The slip that brought me  
To my knees, failed*

*What if all these fantasies*

*Come flailing around?*

*Now I've said too much*

I absolutely loved this song — it was neither too low nor too high, fitting comfortably in the ‘pocket’ of my vocal range. I tried to emulate R.E.M.’s lead—singer, Michael Stipe, and his reedy wail as I sang, thinking back to the song’s melodramatic and dreamlike music video.

R.E.M. were from Georgia, and there, down south, losing your religion was an actual phrase. I’d researched it online, but found conflicting reports of what it actually meant. Some said it meant falling in love, others maintained that it referred to losing your temper. A third source explained that it referred to losing your composure, which was the definition I chose to believe, not least because it encompassed the first two. Stipe had said that "Losing My Religion" was about "someone who pines for someone else. It's unrequited love, what have you". I wasn't trying to sing it about anyone or to anyone in particular, I just enjoyed being able to sing my heart out and, in some small way, pay tribute to one my all-time favorite bands.

All too soon, the final notes sounded. I took a deep breath and glanced at the other teacher. She was beaming. I grinned back, on an adrenaline rush, before we launched into "Sunset Boulevard". This was slower, and I found going from the fast, upbeat pop-song to the quiet, slower musical number to be jarring, and I struggled to find the right pacing. I made it through the song, for all its syncopated wording and long phrases, but as supremely glad when it finished.

As I progressed through secondary school, I found I had more confidence to answer the question of “so what happened to you?”, but I think that this is also due to the fact that secondary school students often have more tact than younger kids. The Young Scientist project also had unintended knock-on effects for me in this regard — it announced to the other students that I had CP without me telling them directly. Naturally, I spoke more candidly about it with close friends, but for the general students who only knew me to see in the corridor, it answered their question of “so what happened to you?”.

I'm happy to say that the school as a whole was very accommodating over the past 4 years. Two teachers in particular stand out — not by 'respectfully' not mentioning my CP, but by being able to have a conversation with me about it where I felt nothing but mutual respect emanating from them. One of them is the reason I have a desire to be a teacher someday. You can spot a good teacher long before you see them in front of a class by watching how they interact with students with disabilities. I've had overbearing teachers and I've had the opposite — teachers who went out of their way not to talk to me, thinking that all a child with CP wants is to be left to their own devices. What you want, obviously, is something between the two. That said, how they deal with students with disabilities isn't the only metric by which we gauge whether someone's a good teacher or not, but I've never found a good teacher who's bad at dealing with disabled students, or a bad teacher who's good with them.

The two teachers I mention above stood out in my mind because they instinctively found that middle ground with me. I remember in particular the first time one of the teachers talked to me about the surgery I was going to have in June 2012. That teacher not only knew about my surgery, but was able to have a conversation with me about it where I didn't feel awkward or self-conscious. It was an unusual, but heartening experience.

That's not to say I never had bad experiences. During one of my first Religion classes of 5th year, we watched "Inside I'm Dancing" as part of a module we were doing on minorities. The movie focusses on two disabled characters in a care facility: Michael, who has cerebral palsy and Rory, who has Duchenne muscular dystrophy. In one scene, the two characters, plus a third, Tommy, are painting with mouth-brushes, and the following exchange takes place:

*Rory: "Is there a mind in there?"*

*Tommy: "Cerebral palsy. Fucks your brain. Don't expect Einstein."*

I hadn't known we would be watching the movie that day, and the quote caught me completely off guard. I laughed when I first heard it, but my head reeled for the rest of the 40-minute class period. I would've appreciated a little warning from the teacher or the option not to have to be in that class one day. After the class, the teacher asked me

if I was okay watching the movie, which felt a little like locking the stable door after the horse has bolted. I smiled politely and said it was fine, but I'd prefer to work in the library rather than watch the rest of the film. I didn't go to another religion class for the rest of the time I was in school.

While I was in secondary school, I joined a youth theater in Limerick. Richie Ryan, the director, is another adult who's made a big impact on me. With Centerstage Youth Theater, I gained enough confidence to venture onstage in productions such as Little Shop of Horrors, Guys & Dolls, and RENT, and only had that confidence because of Richie, who constantly refused to make a big deal out of my CP. I'd arrive at rehearsals, he'd ask me how the leg was, and that'd be that. I would be expected to pull my weight the same as any other cast member. Richie would make accommodations where necessary, but was never patronizing. I have only respect for him because of how he treated me — he epitomizes the correct way of dealing with someone who's disabled: willing to assist when necessary, but never being overbearing or condescending. A lot of the self-confidence that I enjoy today can be attributed to him.

Richie also made accommodations for me during Little Shop of Horrors, which I wrote about on the blog. To give some background, Audrey II is a man-eating plant, and towards the end of the show, my character gets eaten by the plant. Onstage, we had a model of the plant with a hole inconspicuously cut in the mouth, large enough for a person to slip through, giving the impression of being 'eaten'; from there, they can shimmy out the back of the model and offstage:

*Audrey II has grown from normal-plant-size to about 7 feet tall by 8 feet long. I get eaten by it. Originally, the plan was for me to 'fall' into the plant's mouth, and be 'swallowed', however, I can't jump into it, because I don't have enough strength in my legs. [The hole for the 'mouth' of the plant was about 3 feet high and 3 feet back from the edge.] I asked Richie, the director about this, and so now the plan is I get in as far as I can and Seymour [another character in the show] will grab my legs and lift them up and inside the plant.*

Working onstage with a disability also gives rise to some funny situations. I remember a particular incident during a rehearsal for Little Shop of Horrors — a role

where I was playing Mr. Mushnik, a very old and very grumpy man who owned the flower shop in the musical. I'd recently started using a crutch, and had incorporated it into the part. During a tech rehearsal, I was being fitted for a head-mic and the stagehand was making idle chat.

“I was watching you guys rehearse earlier; that limp of yours looked really convincing — good job! Did it take long to learn that?”

“Uh, yeah” I laughed. “You could say I've had some practice.”

It's a credit to Richie that I found myself so at ease as to be able to joke about my CP in such a way — there was a time in the not-so-distant past where such an offhand comment would've made me hugely self-conscious and ill at-ease. In fact, there was a time when I wouldn't have had the confidence to be up there doing a musical in the first place.

Finding adults who can interact with you and your disability without you feeling awkward or nervous isn't common. Outside of my family, I've come across 3 or 4 such people in my life, and it's impossible to understate their importance or the impact they've had on me.



## Chapter Five - The Second Surgery: Classrooms in Coffee-Shops

While I was growing up, knee pain wasn't altogether uncommon. It'd get bad when I did too much in one day, and then I'd have to take it easier the next day in order for the pain to ease. Usually, it was never too strong and rarely did it stop me from doing anything. That changed around the start of 2010, when knee pain started to come more frequently and be a lot worse than I was used to. The physios couldn't discern the reason for it, and I couldn't think of anything that'd changed that might be the cause, so we tried a couple of different treatments. New exercises and bandaging it didn't help, so we tried a slightly more extreme treatment: injecting the kneecap with cortisone steroids and immobilizing it in a cast for six weeks, using a wheelchair to get around.

I had used a wheelchair on and off growing up, and after the first surgery in 2004, I'd spent many hours in one that reclined. As much as I hated wheelchairs being part of my everyday life, I accepted that using one might help put an end to months of knee pain. Over the previous number of weeks, I'd missed a lot of school, been on a lot of different painkillers, and had a lot of sleepless nights. I deeply resented having to use one around school though. I was in second year and had spent so long working to be no different from any of my able-bodied peers. I'd been offered extra time between classes and the use of the school elevator, but I'd consistently ignored them — those would have alienated me, and I was content to use more energy rather than appear too different. With the wheelchair, my movements were a lot slower and labored, it took me longer to get from class to class, and my hip would ache after being forced to sit for hours on end. Despite all the discomfort, I somehow managed to keep the larger picture in mind, as I wrote on Trust Tommy:

*I kind of mind having to use the wheelchair because it's so annoying and intrusive. Then again, you know what else is annoying and intrusive? Slipping somewhere, breaking your leg and winding up in hospital for a few weeks. I think the wheelchair, therefore, is a good idea and I'll definitely be using it.*

Those few sentences sum up a lot about how I chose to deal with my disability, and it's a perspective I've applied to everything from wheelchairs to surgeries to

crutches — I'm not happy to have to do this, but if it'll ultimately be to my benefit, then I guess I'll do it.

As it turned out, though, it wasn't entirely to my benefit. The cortisone injections didn't help me in the end, and the knee pain returned after a few days. Running out of options, Mum e-mailed the surgeons in America, and we set up a meeting in July. They were attending a conference in Louvain, Belgium, and organized for us to meet. (It's yet another example of the surgeons I've been lucky enough to know working to limit the cost the patient has to go: agreeing to meet in Europe rather than the patient having to go to America.) Mum and I went to Belgium for 24 hours and met the surgeons; the specialists in Gillette Children's had seen knee pain like mine before in CP and they knew exactly how to treat it. They were able to see that more corrective surgery was the best way forward and we settled on September 28, 2010, as the date.

Preparing for this surgery was a lot easier than the 2004 surgery. I was older, and therefore a lot more aware of what was going on around me. Less went over my head this time, as I knew what they were doing and what it hoped to achieve. Also, this time round, I had Twitter and my blog to keep me connected, so being away from home for several months wasn't as jarring as it was in 2004. I even set up a separate blog that served as a "hospital diary" for people back home. This entry's dated September 30, two days post-op:

*I wish I had John's ability to sleep anywhere, I really do. Hospitals are always associated with not getting a lot of sleep (or having very bad sleep) thanks to nurses coming around to check your BP and such, and to move you every 2 hours. Luckily, I've nothing to do here except exist, really, so I sleep whenever I can. My leg, which is in a soft cast, is incredibly sensitive. Moving me from my side to my back is grand, but moving me onto my side can lead to very bad pain if it's prolonged. It's not their fault but boy, does it hurt. The doc was just in with some good news. Since my pain's quite low (Never more than 3 on their 1-10 scale. Leg's in a bit of discomfort but totally manageable) and I'm responding quite well to semi-solid food (mushy pasta, not actually too bad), everything (IV, epidural, catheter, soft cast) gets removed tomorrow.*

While I was in hospital, I used to get a lot of interaction with people on Twitter, who'd wish me well or ask how I was getting on. Almost every morning, the user @JustAnotherTrnd would ask how I was and provide encouragement. It was only when I looked closer at the account that I realized that the account was 'written' by two anthropomorphic hospital therapy dogs, named Dusty and Hurley. I love dogs, and had met a particularly friendly one called Trooper in hospital, so I replied to the account. I'd never heard of Shari, their 'scribe', but here she was, providing support and asking how I was doing daily. Whenever I tweeted that I was trying something new in physio, they'd provide encouragement. It was incredibly heartening. At one stage, Shari asked me for my address and a few days later, a long-sleeved T-shirt arrived at our rented apartment, bearing the inscription "LIFE ROCKS" in bright red letters, with "(your experience may vary)" underneath it. The fact that someone whom I'd never met, who I only knew through Twitter, would take the time, money, and effort to send that to me made a big impact on me. When you're in America for 3 months with only your parents, it's easy to feel isolated and upset, and it's people like Shari who prevent that from happening, and I have nothing but the utmost respect for her and those like her.

(The following year, in July 2011, I visited New York City, and Shari put me in touch with Emma, a young lawyer who lived there. It turned out Shari had donated a kidney to her in 2000, despite the fact that she didn't know her previously. Emma and I met for dinner in Sarabeth, just off Central Park; she turned out to be a fascinating person, and I had a fantastic evening.)

I got out of hospital the Sunday after surgery, and spent most of that day in bed, incredibly nauseous and incapable of concentrating on anything due to a pounding headache. I'd been placed on another regime of painkillers and while taking the tablets themselves wasn't a problem (as it had been after the surgery in 2004), I decided to stop them after that Sunday because the pills made me incredibly drowsy and nauseous. I decided that that a certain amount of pain and discomfort was a small trade-off for lucidity and the ability to get out of bed. By the time we realized that the pills were supposed to be taken with food, and that taking them on an empty stomach was what caused the ill-effects, I was well enough not to need them.

After being non-weight-bearing for three weeks, we went back for the post-op visit, and the surgeon was very pleased with my progress. When you're recovering from

surgery, what you miss isn't often what you expect. When I was allowed move around without a wheelchair, I realized how much I'd missed little things like sitting beside Mum and Dad at a table and being at their height. On Trust Tommy, I recounted my first trip to physio, dated October 19:

*Doing physio yesterday was bizarre because my legs didn't feel like my own. Not so much a case of having aches where I didn't know I had muscles so much as "Hello physio, I've forgotten how to use this muscle — can you show me how?" It's kind of odd and scary how weak you become when you don't use a couple of muscles. So, that's an update on how my legs are doing. Long may it continue!*

That surgery took place during my third year of secondary school, which meant that, surgery or no surgery, I'd be sitting the Junior Cert. at the end of the year. As soon as I felt well enough, I went back studying. Initially, it was incredibly tough to juggle an extensive physio regime (it was around 4 hours a day between passive and active stretching and strengthening) and schoolwork. I was thrilled when I got the results of those exams the following year; they can largely be attributed to the work I did while in the US. After doing physio in the morning, I'd head to a café, put on some music (usually Girl Talk's "All Day" or the Broadway cast album of "American Idiot") and work for a couple of hours. I'm not entirely certain why I prefer working in cafés to working at home. Maybe it's because a change is as good as a rest, and it was refreshing to get out of the apartment. Maybe it was because I wanted human company that wasn't my parents — I did get to know most of the waitresses of the cafés by name, and they soon came to know the ginger teen with the crutches and the funny accent. I soon built up a routine where I'd work for two hours, then take a half hour off to play online chess. I would also happily look at the throngs of people passing me, people-watching and making up stories about them for my own amusement.

Most of my efforts were concentrated on Science, Geography, History, Maths, and parts of English. For most of it, Mum and Dad helped me out — Dad was always willing to help with Science and Maths, and Mum did History and read through Romeo

& Juliet with me, doing a scene a day. I had always had a reasonably good memory, so learning off dates in History or quotes in English was never too much of a problem. Looking back, Trust Tommy provides a great diary that I can use to chart how I got on after the surgery. It's written contemporaneously, which is a definite bonus. It being a diary, you can definitely see that as the initial discomfort ease after the surgery, a hopeful optimism takes its place:

I've been walking more and more each day, which is great because it's one more step back to normality. I'm glad to have some semblance of independence back again (odd fact: I set foot in our kitchenette here for the first time yesterday). Pain levels at zero 99% of the time except when I hit it off things. Still quite weak but I can do more each day, which is neat. Seeing things being better every day is undeniably heartening.

Again, a definite sense of just having to get on with things prevailed while I was in America. I had to study for the Junior Cert. and I had to recuperate after more surgery. I went with and did the work because I felt it was my only option. It was definitely tough at times, when my days seemed nothing more than study and physiotherapy. There were, undoubtably, lighter and more fun moments too. At the end of the day, I was still with my parents, and we made the best of things. As a city, Minneapolis is quite nice, even when it's -30°C outside and you have to try and push a wheelchair through two feet of snow if you want to go anywhere.

Well, actually, you rarely found yourself having to push a wheelchair through the snow, because Minneapolis is fantastic for not letting their intense weather slow anything down. Almost as soon as the first signs of a heavy snowfall appear, they're out there clearing the roads and salting the sidewalks. Not only that, but we were able to go from our apartment many of the shops and restaurants downtown without ever stepping foot outside. The Minneapolis Skyway System is a series of enclosed footbridges that links 69 full city blocks over 18 kilometers. It took about three times as long to get to the library or my favorite café going by Skyway rather than by street, but it allowed me to walk every day, something that was important for me when I was relearning to walk after the surgery.

In a lot of ways, my parents and I created a life for ourselves when we moved to the States for those 3 months. We joined the library, spent hours in the bookshops or the cafés, and even got to experience a traditional Thanksgiving celebration with some friends. All in all, it was an easier recovery than the surgery in 2004, but not as easy as the surgery in 2012. Having been through it all before, knowing what to expect, was a lot of help. I spent a lot of recovery time going to the cinema or the library or to bookshops. It's incredibly easy to get cabin fever when you're in an unfamiliar city, especially when you're in another country away from friends and family, so distractions can be useful for making the whole experience a lot easier.

## **Chapter Six - Living Your Life: Having A Disability, Not Letting Your Disability Have You**

Writing this book had two aims. First and foremost, I wanted to write a book that summed up who I was in the face of my disability. Cerebral Palsy doesn't define my life, but it's shaped who I am, and I wanted to document and analyze that. Secondly, I wanted this to be a book for others. It's for anyone with a disability who wants to know how others deal with their impairments. When I announced that I was writing this book on Twitter in August 2012, I got a couple of replies and e-mails from people who thanked me for writing about disability from a first-person perspective. In being for others, I wanted the book to be for people who weren't disabled too — the people who wonder what it's like to have a physical disability.

To give a short answer: it's a mixed bag. There are days when it feels like the only thing people notice about you and you make the mistake of believing that it's your defining characteristic. That's how I felt for a lot of primary school. In 2008, when I wrote a page for my blog about who I was, this was the very first sentence:

“Tommy Collison is a 14 year old student with Cerebral Palsy.”

Mistakenly, I thought that my CP was such a big part of me that it should be mentioned front and center like that. It was as if I'd written “Tommy Collison is a 14 year old student with red hair” or “who sleeps in a bedroom with southern exposure” or “with a birthmark on his right wrist”. None of those are defining characteristics, and neither is having CP. When I introduce myself to someone, I never say, “Hi, I'm Tommy, and I've a birthmark on my right wrist”. No, I say something like, “Hi, I'm Tommy, and I'm a far-too-enthusiastic drummer”. Then, the two of us engage in a discussion of our favorite music, and, nothing is said of the limp.

When I wrote that I was 14 and had CP, I made the mistake of letting my disability define me. It was only later that I realized that when people meet me, they tend to notice my enthusiasm, not my limp. When they get to know me, something I said to them is what sticks out to them much more than the fact that my movements are slightly slow or labored. Human beings in general are pretty adept at discerning what's

important about someone and what's not, at least for the purposes of the conversation they're having, and so I needn't have worried about CP being the only thing people knew me for.

There are other days when your disability seems to be the only thing you can focus on. Usually, that's when you're in pain. All you can focus on is how limiting it can be on you. Honestly, I think everyone with any form of disability gets those sort of days; the days where you wonder how you could possibly live any other way but inexorably governed by your limitations. But, like everything, those days do pass. You realize that the way to live your life isn't so much 'in spite of' your disability as much as 'in tandem with'. It's not something that can be ignored, it's something that has to be accepted. That's not to say you have to love it, or anything, but you can't ignore it. I'm no sort of psychologist, but I'd postulate that people with disabilities are never truly happy unless they have, even grudgingly, accepted their disability; I certainly wasn't. Accepting it does not mean letting it define you.

One of the ways that you can stop your disability defining you is to become outrageously passionate about something else entirely. One of the things I focussed on in this regard was drumming. During a school concert in primary school, I realized that I really liked how they sounded, and so I started lessons. I think that a large part of the reason I'm still drumming today is the initial enthusiasm of my drumming teacher, a twenty-something named Keith. Like Eoin the rehearsal pianist, he obviously and unashamedly adored the drums, and all enthusiasm is contagious — I fell in love with drumming and got a kit the following Christmas. While I was getting lessons, I wondered whether my CP would impede my ability to play, since all four limbs are required in equal measure to play. Luckily, I found that they didn't stop me at all, and playing probably improved the strength and dexterity of my left hand and right leg.

When I was growing up, my Dad would read the Harry Potter books to me. (Each night, he'd would read a chapter to me, and to this day, I feel guilty for all those times I fell asleep before he finished it.) I really enjoy the series, and I've huge respect for J.K. Rowling as a writer for creating such vivid worlds and characters. There's a scene in the second book, *The Chamber of Secrets*, that's stayed with me in the years since I first heard it. Dumbledore, the school's headmaster, says that:



“It is our choices, Harry, which show what we truly are, far more than our abilities.”

I take this quote to include “or our disabilities”, and I absolutely believe that our choices shape who we are much more than any disabilities we might be born with. The fact that I love to drum is a much bigger part of who I am than the fact that my muscles are tight. Even though Dad and John sometimes jokingly wonder if drums are a real instrument or not, I’ve been playing for over five years and it’s been a lot of fun for me.

I’ve consistently refused to let CP get in the way of my life any more than is absolutely necessary, and that’s been hard, but it’s also shaped who I am today. Stephen Hawking, who has motor-neuron disease, once said that “People need not be limited by physical handicaps as long as they are not disabled in spirit”, and, while it’s a bit twee, I think that’s incredibly true. A physical disability is twice or three times as debilitating when you allow it to interfere with the rest of your life — you have to compartmentalize it, focussing on the things you love that it doesn’t inhibit. I’ve always loved writing, at least in part because it’s something that Cerebral Palsy doesn’t affect. I’ve seen people who’ve been “disabled in spirit” and I’ve seen those who, like me, have learned not to let it define you by focussing on something else that you’re passionate about. Whether that’s computer programming, painting, or writing doesn’t matter — all that matters is that you don’t let your physical disability rule your life.

How has CP shaped who I am? Well, I think I’m a lot more independent than I otherwise might have been. Back in July 2011, I posted this on Trust Tommy:

I always love being busy, and I often wonder if it’s in spite of Cerebral Palsy, or maybe because of it. Am I always going up to Dublin, doing internships, trying new things and so on because, subconsciously, I think people don’t expect me to be able to? It’s something I often wonder, but either way, that’s the sort of person I am.

Looking back on that now, I can say with a fair amount of certainty that it’s because of my CP that I’m as independent as I am. It was precipitated by the fact that blogging meant that I had friends in Dublin as well as Limerick, but the fact that I was so determined to be able to take the train there on my own is because of CP. Growing up, I think that I thought people didn’t expect me to be able to live a full life, and that I

subconsciously rebelled against the notion by never shying away from going to Dublin for a day or doing a lot of physical activity soon after surgery. In 2012, I visited an air traffic control tower, which required going up and down two flights of narrow stairs, two days after surgery.

It's as if being afraid of stopping short of what I'm capable of has swung the pendulum to the other extreme and I often overexert myself. In 2010, after weeks of rehearsals, recuperation from cortisone injections and two two-and-a-half-hour performances of RENT, I found myself physically spent the following week, almost completely unable to leave bed due to tiredness. Having absolutely no energy was totally worth it, though, since doing RENT was one of the best experiences of my life.

A doctor once confided in me that, of all his patients, I was the one he had to watch closest to make sure that I never overdid physical activities; in his opinion, I was the one most likely to do too much and damage something. I'll admit that I took it as a bit of a compliment — it suggested to me that I wasn't letting my disability get in the way of my life, exactly how I wanted things to be.

Getting back to question at hand, living with a physical disability on a day-to-day level is making a lot of small adjustments as you go, the same as riding a bike or flying a plane. At its most basic, though, it's having a certain mindset, where you're looking at a situation and trying to see if you'll have to make adjustments that deviate from the norm. For example, if I'm going up to Dublin for the day, I've to make sure that I know where I'm going, because I can't afford to expend the energy to walk around looking for somewhere. If somebody tells me that it takes 15 minutes to walk somewhere, I've to adjust that for my own pace and leave myself 25 minutes to get there. Whatever I'm doing that day, I've to make sure that I leave myself enough energy to get back to the train station in the evening. If I'm somewhere that everyone's standing around chatting, I have to pluck up the courage to ask for a chair.

A question that sometimes comes around is whether faith has any part in my life. I never really found a way to interact with or believe in a higher power that felt real or genuine to me. I don't think that was necessarily because of having cerebral palsy, although it may well tie into the fact that CP, like lots of other little things, shapes who you are and what you believe. My experiences with religion are almost entirely made up of experiences of the Roman Catholic Church, and I never felt comfortable in close

proximity to it. Fundamentally, we disagreed on a number of issues, but also, I felt uncomfortable with the idea that a god was there to help me through my disability, or that if I achieved something, it was thanks to that god. I rebelled against such an idea, which was tossed at me a number of times during the years. It annoyed me because, to me, it felt as if my pluck and perseverance were down to a god rather than to me. Frankly, I think that phrases like “God made you very brave during that surgery” (which I’ve actually been told) undermine the tenacity and resolve that allows me to face cerebral palsy treatments. The same goes for the people who say things like “Have you tried praying to God to cure your disability?” (also something I’ve been told) or even “God gave you CP to make you a stronger person” (also this). Attributing the strength, courage, and determination of someone who’s disabled to a higher power rather than to the person themselves leaves a very bad taste in my mouth. We deserve to be proud of ourselves, not some omnipotent deity. I wouldn’t say that having a disability has made me bitter toward religion; I’m not a die-hard atheist, I just quietly think it has no place in my life.

Over the last few years, I’ve read many blogs written by people with CP, and it’s allowed me to look at how different people choose to look at their disability and how they deal with it. Sometimes, I’d see sentiments like “Embrace what you were born with because it’s beautiful”. Disabilities aren’t beautiful — they’re hard. They might even be the hardest thing you ever face. They’re a struggle. You might come out of that struggle a better person, but your disability is never anything more than an impairment. To treat it any differently, to claim it’s “beautiful”, is not to give the credit your perseverance deserves. If you don’t allow it to interfere with your life any more than it has to, you deserve the credit, and, if anything, your willpower’s the beautiful thing. The fact that you overcame it to live your life on your terms, not your disability’s, is the beautiful thing — the disability is never anything more than the insidious force that pre-empted the struggle.

It’s the same with people who encourage and further the idea that there’s no such thing as a disability, such people are just “differently abled”. I first heard that phrase 8 or 9 years ago, and even then, I rejected the sentiment. I’m not differently abled: I’m disabled. I have less function in certain muscles than is normal. Semantically, “differently abled” is a terrible way of describing someone with a disability. My mum can

speak French, and I can't. My mum's differently abled, because she can do something I can't, but she's not disabled. People who use the phrase "differently abled" are doing people with disabilities (and the English language) a disservice. You could argue that because my legs work 'differently' to the norm, I'm "differently abled", but that's not being descriptive — they don't work differently, they work worse than normal. Another way of saying it? Being disabled. It's not a dirty word.

In order to live as normal a life as possible, people with disabilities need to make compensations. I think that's a truth that needs to be accepted by disabled people pretty quickly. To me, a person growing up with a disability is faced with a clear choice with regard to stopping themselves becoming "disabled in spirit": they can be pragmatic and work out how to live as normal a life as possible within the constraints of their impairments, or they can shroud themselves in euphemisms of being "differently abled" and the thought that their disability's "beautiful". I'm not saying which choice is quantifiably right, but I certainly believe that the former decision is the quickest way to leading a normal life, which surely is everybody's goal.

One of the most common questions I get when I'm talking to people about my cerebral palsy is whether I wish I'd never had it. It's a tough question. What's worth realizing is that who you are is decided by hundreds of individual traits and experiences, so if I didn't have cerebral palsy, I wouldn't be who I am with it. Because of that, the question boils down to whether I'm happy with who I am — would the resulting change in who I am be worth not having cerebral palsy? The answer to that question is no: I'm happy with who I am, and being different is too high a price to pay for not having cerebral palsy. I'm lucky to accept it for what it is and not impede me doing what I love, so I wouldn't change it even if I could.

## Chapter Seven - Third Surgery: Fraternal Care

My next major surgery happened on June 7, 2012. It was significant because it was the first time I'd been in hospital without my parents also being there: my brothers were my 'carers'. Earlier in the year, before any surgeries were mentioned, my parents had been planning a trip abroad to celebrate their 25th wedding anniversary. They organized a holiday to cycle the length of France, a distance of some 1,100 miles. They'd spent their honeymoon cycling around Cyprus, and so this was seen as their "second honeymoon". In March, when I met Dr. Novacheck at a CRC-organized conference in Dublin, they'd already started organizing the trip — booking the ferry and so on. June was the best time for the surgery Dr. Novacheck was suggesting, since it would give me the summer to recuperate and my schoolwork wouldn't be affected. At first, both Mum and Dad wanted to cancel their trip and come with me for the surgery, but Patrick, John, and I convinced them to go on their holiday as planned; John and Patrick were more than willing to take care of me in Minneapolis. The original plan for June had been for me to stay with Patrick and John where they lived in San Francisco while Mum and Dad were in France anyway, so it was really just a case of spending the first half of that month in Minneapolis rather than San Francisco as I recovered from surgery. I looked forward to seeing how the whole surgical experience would differ with brothers rather than parents. For the first week in Minneapolis, John would look after me, and for the second week, Patrick would take over, since neither of them could afford to take the full time off work. I had always been fiercely close to both my brothers, and so I never felt worried that they wouldn't be as good at caring for me as Mum or Dad were.

I always enjoyed spending time with John. He was fairly quiet, and wasn't one to make idle conversation. That said, as far back as I can remember, I could always count on him giving me advice if I asked for it — on everything from dating to schoolwork to this book. Further, he was always incredibly generous with his time, both to me and others. He was also moderately obsessive, devoting huge amounts of attention and energy to whatever his focus was at the time. It didn't even have to be his focus — he was, in his own words, more than happy to obsess over your things as his. In one of his college entry essays, which was written as a letter to a prospective roommate regarding what to expect, he wrote:

I'm just extremely obsessive about... life. [...] I guess I mean that my life and thoughts tend to be slightly... affected by whatever I'm currently concentrating on. In the week leading up to my flying theory exam, I talked and thought of little else. I tried to estimate the runway friction index our floor would have. I tried to convert my bike's speedometer to knots. The nice coffee shop lady wondered why I was reciting cloud types (nimbostratus latte, anyone?). I converted numbers from magnetic headings to true headings, even if they weren't headings at all (they were grocery prices, I think).

I guess you can expect to know what my current focus is, all of the time. I could be beginning Arabic or repairing my bike or learning the concertina. [...] More importantly, I'm as happy to obsess on your things as mine. I'm generous with my time and efforts. I'll stay up all night making you flash cards for your biology exam (in English even, if your Arabic isn't up to scratch yet). I'll repair your bike too.

I arrived in Minneapolis on Tuesday night, ahead of surgery that Thursday. On the Wednesday afternoon, John and I went shopping for groceries, which were in short supply in the rented apartment. While wondering what to do for dinner, I volunteered to cook dinner, happy to have something external to concentrate on the night before surgery. The last thing I wanted was just to be bumming around the apartment, focussing on nothing but my impending hospital visit. I cooked pasta with meatballs, something I'd done a handful of times at home — I wanted something manual that'd distract me, but not something unfamiliar that required a lot of concentration. John went for a run and I put on some Green Day through the stereo system, which was my usual source of distraction and way of dealing with stress. After dinner (which turned out great, by the way), John and I watched *The Maltese Falcon*, a quirky black-and-white crime movie from 1941. We hadn't seen the movie before, but it's regarded as one of the best movies of all time. Plus, it was set in San Francisco — neither of us needed much more reason than that.

The next morning, our routine didn't change just because I had surgery around noon; both of us enjoyed working in cafés, so we headed to one that John had discovered — a little place on Nicollet and East 43rd called Anodyne Coffee. Because I wasn't supposed to have solid food past 4am and any liquid past 10.45am, I stuck with

Sprite. To distract myself, I played a couple of rounds of chess online, again looking for something external to focus on that. On the way to the hospital, John and I blasted music on the car's radio rather than talk about the surgery. John was great for not making a big deal out of something unnecessarily — if I was concerned about anything, it certainly wasn't because John kept bringing it up. He didn't ask me how I felt about it or if I was nervous or anything; if I wasn't going to bring it up, he wasn't going to probe. It was comforting to know that he was there if I did want to talk about it, but we mostly talked about other stuff.

Once we got to the hospital, I pretty much switched to autopilot. Pre-op is always my least favorite part of the surgery experience. Once you wake up, it's pretty much over and done with and all you can do is recover, but before the surgery, you can't help but feel incredibly nervous. The staff at Gillette Children's are absolutely fantastic in this regard — my uneasiness was always partially assuaged by their friendly demeanor and the fact that I always felt that they were totally in control. There's a lot of differences between the American health system and the Irish health system, but one thing I've always noticed is that in America, nothing ever seems to come as a surprise to them. I've joked with friends and family that being in hospital there feels like being on a conveyer belt; as a patient, you feel like the thousandth-and-first person getting this particular treatment. While the conveyer belt analogy seems like a negative comparison, it's definitely not. What it means is that the staff know that by the first day post-op, you should be managing certain milestones, and by the second day, you should be achieving a different set of milestones. During my three surgeries in America, their confidence and familiarity with their processes always gave me a lot of confidence and made having surgery over there a lot easier than at home.

When I woke up, I found myself in the post-anesthesia care unit, or PACU. The first thing I noticed was that I was a lot more alert than I normally felt after surgery. Waking up from anesthesia is usually a very gradual process, like surfacing from a deep pool and your full senses and perceptions coming back piece by piece. Usually, you don't feel "right" for several hours — the previous two surgeries, I had laid in a daze for the rest of the day as I slowly recovered from the effects of the anesthesia. This time was very different, though, and I sensed that immediately: I was alert, talking in coherent sentences with the PACU nurse. It took a gargantuan effort not to throw up, but

mentally, I felt surprisingly good. I was later told that the reason I felt so responsive and clear-headed was that I had been under anesthetic for a comparatively shorter time than the last surgeries, and the recovery time from anesthesia is directly proportional to how long you're "under".

When I arrived at the room where I'd stay for the next few nights, I was awake enough to realize that it was the same room as I'd stayed in 2010. John arrived not long after that and we chatted for a while. I had my laptop with me, and iTunes movie rentals proved to be a reasonably inexpensive way of keeping myself entertained while in hospital, and I definitely recommend it to others. I also read Ewen Montagu's "The Man Who Never Was" a historical account of a World War Two deception entitled Operation Mincemeat, because I intended it to form the basis of a history report that all Leaving Cert. History students do. The report is on a subject of the student's choosing and is worth 20% of their overall grade.

The hospital also had internet access, so I could still read blogs and update my own:

**All in all, I'm in good spirits, though. My 18th birthday is tomorrow and I should be discharged from hospital later today.**

On the whole, the fact that I turned 18 just after surgery wasn't hugely relevant, apart from my not wanting to be in hospital on my birthday. The fact that I was underage and not accompanied by a recognized guardian was important, though. Because I was a minor at the time of the surgery, consent had to be obtained for everything the medical team did, which meant that Mum had to be read several forms over the phone in order for her to provide consent. We had assumed that John could consent in her place; had we known that he couldn't, we might've asked Dr. Novacheck in March if we could have a date in June after the 10th. I'd have liked to consent to my own surgery just once — although I'm not calling for further surgeries just to give me that chance!

Luckily, I recovered from the surgery faster than was expected, and was discharged on the Saturday, a day before my 18th. Later that day, John and I went into downtown Minneapolis to grab some lunch — it served as another example of the



difference between John and my parents taking care of me: John found us a great restaurant, but it wasn't particularly wheelchair accessible — Mickey's Dining Car was, somewhat unsurprisingly, housed in a railroad car, and therefore quite narrow. It served great food, and I had no problems getting around it, but it wasn't the easiest place I could've gone. While we ate, John and I decided what to do with our afternoon.

I was a bit tired from a busy morning (getting the soft cast off, removing all the wires and tubes, getting X-rays, and taking my first post-op steps), but otherwise I felt great. It's true that I try to push myself a little further when I'm with other people in order to keep up with them, but I never mind doing so. Since nobody can tell when they've reached the point where they're pushing themselves too far, I prefer push myself a little further rather than fall short of what I'm physically capable of; it's part of not letting your disability rule your life.

Eventually, we decided to drive out to South St. Paul Municipal Airport, 10 minutes out from St. Paul. It was a quiet Saturday afternoon, so we hoped that someone in air traffic control would be willing to give us a quick tour of the tower. I've got an interest in aviation, and John's a qualified private pilot, so a tour seemed like a great way of spending an afternoon.

The air traffic controller who showed us round was a chipper 40-something-year-old in a Stetson. I watched as he chatted about flying with John, who was obviously enjoying himself. We took the elevator up to the 4th floor, but when I stepped out of it, I found myself in a corridor with offices leading off it, and not an air traffic control tower. It turned out that the tower itself was up another two flights of stairs. I'd been taught how to manage stairs before I'd left the hospital that morning, and so I went up and down the two flights of stairs without a problem, even though it took me a long time and took a lot of energy. I hadn't known I'd need to climb stairs before I went to the airport, but even if I had known, I don't think I'd have done anything differently — seeing how much John enjoyed himself up there was worth it. As I caught my breath at the top of the stairs, I remembered that not all brothers would agree to take a week off to take care of their younger sibling and ask nothing in return; I felt that not complaining about the stairs was a small token of unspoken gratitude. I'm not saying that getting up those stairs was easy, but it was worth the effort.

The next day was my birthday, and we spent most of the morning in a café, this time the Butter Bakery Café on Grand and West 36th. Over the next few days, I finished “The Man Who Never Was” and continued working on my first experiment in publishing. By this stage, John had gone back to San Francisco and Patrick had taken over. I get along with both brothers equally well, but I think that I’m more similar to Patrick than John in terms of personality. While he worked on things to do with Stripe, his second start-up which he founded with John in January 2011, I continued working on publishing a book online.

I’d recently become a registered publisher on the iTunes Bookstore, which allowed me to publish stories online, available to anyone with an iPhone, iPad, or iPod touch. A few days later, I also set up an Amazon publishing account, and the book became available on all Kindle devices, too. I’d wanted to be a writer for as long as I could remember, but had always considered it an unattainable pipe-dream until Steven Troughton-Smith, a close friend and developer, introduced me to self-publishing online in a Starbucks in April 2012. To call what I went on to publish ‘a book’ might be a slight overstatement — it was a group of five short stories and essays, clocking in at just under 50 pages. When I published “A Certain Freedom” in June 2012, what excited me most wasn’t that I had ‘published a book’, but that I had the potential to publish something more. I’d removed any logistical barriers; nothing stood between me and writing and publishing something more substantial. I was happy that I’d published “A Certain Freedom”, but mostly, I was looking to the future.

The following Wednesday, I had the last meeting with Dr. Novacheck before I left for San Francisco, where John and Patrick lived. He examined the incision site and said that it was healing well. I was instructed to keep weight off the leg for 3 weeks but that otherwise, everything looked great. Patrick had a meeting in New York, so I flew to San Francisco from Minneapolis on my own. The 3-hour flight was pretty tough, since the leg was in an immobilizer which stopped it bending beyond 60°. I ended up taking what was only my second post-operative Valium tablet. I hadn’t taken any medication after my surgery in 2004 because I wasn’t used to taking pills, I didn’t take any medication from the day after I was discharged after my surgery in 2010 because it made me drowsy, and I didn’t take any medication after the surgery this time around because the medication they gave me still impaired my ability to concentrate. I took Valium on the

flight, though, because the pain and stiffness was almost unbearable. I said to myself as I took it that being drowsy didn't matter, since I was flying — and anyway, drowsiness was better than being in pain. I forgot though, that Valium needed to be taken with food, and found myself drowsy and with a searing headache. In short, the flight to San Francisco was extremely tough.

I spent around three weeks in San Francisco. In some ways, it's a great city to recover from surgery in, and in other ways, it's a terrible choice. It does have an abundance of great cafés where I wrote most of "A Certain Freedom", and the public transport is uniformly wheelchair-accessible. On the other side, though, taxis are incredibly hard to come by and the topography of the city is completely unsuitable for somebody in a wheelchair. John and Patrick were at work for most of the day, so when I tried to get around the city in my rented manual wheelchair, I had immense difficulty navigating San Francisco's hills. Often, the uneven surfaces would extend to pedestrian crossings — I'd be crossing the street and, halfway across, the chair would get stuck on the crest of the hill, leaving me stuck in the middle of the road, facing a row of cars after the light had changed to green for them. On one occasion, someone in one of the cars had to physically get out and help me the rest of the road.

Because of my difficulties with that wheelchair, I found myself sticking with crutches, even though I tired far quicker. This presented a different problem: about a week after I arrived in SF, I was standing on the corner of 4th and Mission, leaning on two crutches and checking the time on my iPhone, knowing I was late to meet some friends and go to the cinema. The next thing I realized was that there was someone standing near me — so close I noticed him among the throngs of people at the intersection. I didn't see or hear him as much as sensed him, but as soon as the thought registered in my head, the guy bumped into me, two strong hands closing around mine, fingers determinedly clawing the iPhone out of my hand. I looked up, and saw a youth barreling down the street, scattering groups of tourists and eventually disappearing round the corner onto Market.

Even though I was unhurt, and was able to contact John from a passerby's phone, the whole incident left me shaken. Of course, an iPhone's meaningless in the scheme of things, but an event like that leaves its mark on you. I'd never been robbed or mugged before, and even though it sounds childish, it was the first time I truly realized that bad,

scary things happen in the world. John and Patrick were busy for the rest of that evening; I didn't want to bother them, so I got in touch with some friends from Ireland who were staying in San Francisco, and asked if I could spend a few hours with them. Eventually, I chose to stay the night on their camp bed, unwilling to go outside alone so soon, even if it was only for the time it took me to get a taxi or public transport home. It's hard to put into words how much I appreciated being close to someone I trusted that night, and I imagine that everybody who gets robbed or mugged feels much the same way. The next day, a friend of mine snuck up on me and pretended to steal my laptop, and I don't think I'll ever forget the sense of sheer terror and helplessness that I felt. I don't resent him for it, but it was incredibly frightening all the same.

Was I targeted on that street corner because I was on crutches? Probably, because I was an easier target than someone who could've run after the guy. That impacted on me — since then, I've become a lot more wary in public, which is definitely a good thing. I just wish that learning that lesson didn't come at the cost of my iPhone.

As I write this in August 2012, recovery from the third surgery is still ongoing. So far, it's been on a definite upward trajectory, though. I still have to regularly alternate between sitting and standing, and I have to do a handful of stretching and strengthening exercises to get walking independently again. I'm about to start my final year in secondary school, too, and juggling schoolwork with the need to do exercises is going to be the most important thing of the next few months. I'm ready to take it on, though.

## Postscript - Beat It

*"Would you tell me, please, which way I ought to go from here?"*

*"That depends a good deal on where you want to get to," said the Cat.*

*"I don't much care where—" said Alice.*

*"Then it doesn't matter which way you go," said the Cat.*

*(Alice's Adventures in Wonderland)*

I was lucky enough that, as a toddler, my parents chose to start me down the road of an aggressive program, and then later as a 9-year-old child, of surgery. I had parents who chose action rather than inaction, who chose to give me as normal a childhood as possible rather than treat me as different, and who chose to push hard to give me the best shot of an independent life rather than accept that there wasn't much to do to improve my condition. And for all that, I can never thank them enough.

That said, I've come to the stage where I can't be relying on my parents to put me on the right road — I need to be the one who decides what the right road is, and stick to it. I'm lucky in that my parents instilled a lot of responsibility in me, even as a young child, and so the switchover of the responsibility of managing my CP from my parents to me has been really successful. Right now, I'm 18, and it's up to me to continue along the road of keeping flexible and staying active.

The quote from "Alice's Adventures in Wonderland" underlines the importance of knowing what you want to do and setting goals to achieve that. If you don't know where you want to go, any road will take you there. For those with physical disabilities, I think it's especially important for us to know where we want to be. For instance, I think I have the capability to walk independently, so I'm slow to settle for anything less. I need to find out what's stopping me — probably strengthening exercises for a set of muscles — and I need to do 10,000 of those, and then take stock of where I am. If I'm walking independently, I've achieved my goal — if not, I need to look at where I'm going and maybe change direction.

I wrote this book in the space of not much more than a month, but it was in gestation for a lot longer. In fact, I think I felt first inklings of desire to write a book like this when I

was very young. Years ago, I didn't think that writing a book was something I could manage to do, but now I know that it is. Many of the chapters of this book are based on blogposts, others come from discussions I've had with friends or family over the years. How easy it was to write varied from being a straightforward walk in the park to where I'd spend three hours trying to get two sentences right before scrapping them. In some parts, I was trying to write about thoughts, feelings, and memories that I had never discussed with anyone, trying to articulate them into words and sentences that flowed. It was rarely easy, but it was always rewarding.

As I write this, I'm about to start 6th year. Next year, all going well, I'll be starting college, although I'm not entirely sure where or doing what. Since John and Patrick went to college in America (although they both went on sabbatical to work on startups before graduating), I'd love to go down the same route. I spent most of June in San Francisco, and it reminded me how much I enjoyed being nearer them.

Above all, I'm looking forward to the future. I'm lucky enough that I inherited the view of life that my parents had: that life's an adventure and there's always something to do and explore. Happily, I haven't allowed my CP to interfere with that way of thinking, and I've had a couple of adventures over the last few years, and will continue to have them in the future, irrespective of what I end up doing.

To finish, I'd like to talk about a question I got about my CP. To date, it's probably been my favorite question, even though it's been asked only once: what do I wish I'd known? What would you tell 5-year-old Tommy, if you could? In my mind, the question roughly corresponds to what I'd tell my child as they were growing up if they had a disability. I think I'd probably write them a letter.

August 17, 2012

I owe everything I am today to my parents, and so I can only hope to live up to half of what they are. They're the most loving, caring, and dedicated parents anyone could ask for, and I hope that I can be the same for you.

Having a disability is tough, but you can handle it. I did. It was hard — it was probably the hardest thing I did, but I did it. And so can you. There are some days when it's unimaginably difficult to get out of bed and face the world, but it's possible.

So, how do you beat your disability? You beat it by never letting it define you. I wasn't a 14-year-old who had CP, I was the 14-year-old who loved drums, who read every book he could lay his hands on, and who probably played his music too loud. As people, we're not defined by our abilities or disabilities — it's our choices, our aspirations, and our attitudes that define us. So, go out there and be outrageously passionate about something.

You beat it by knowing where you want to be — be that on crutches or walking independently — and then working your ass off to get there. You beat it by never settling for less than what you can achieve. You might have a disability, but don't let a disability have who you are.

You beat it by setting goals. I could quote life mottos like “don't wait for your ship to come in, swim out to it”, but nobody listens to those. Having said that, they are fundamentally built on truth — managing your CP isn't something that's going to fall into your lap as you sit at home moping, but you can absolutely work towards doing so. You beat it with pragmatism — you'll probably never be a professional footballer. Or an astronaut. Or a stunt double. Or a boxer. You're faced with a choice: let yourself be constantly held back by it, or shrug it off and focus on all the things you can do.

And then, if you manage all that? You'll have beaten it; and, more importantly, you'll have the sense of satisfaction of leading a full life despite your disability, and that's an incredible achievement.

—Tommy

## **About The Author**

Tommy Collison is a student and writer. He is currently a secondary school student and lives in Limerick, Ireland.