

Sliding back into the car, I take a moment to fill my lungs with air a few times over as the excitement and fear hit me all at once. I've met a new pain specialist, a man who finally has a sensitive ear to my situation and is prepared to offer me the medication my body wants, doesn't need - but craves. Not because I'm about to get some high or have a few minutes euphoria, or the ability to block out the world around me but because it will make me feel normal again. It will allow me to go about my days again with energy and enthusiasm.

It has never been about getting some kind of 'high' or a way to disengage from reality for me. Opioids have only ever been about giving me the strength and ability to get through the day and night. I hate the feeling of being out of control which is why I never drink or take any other kind of mind-altering medication. It depresses me greatly that I have to depend on these tablets and I don't think a day ever passes that I don't wish or wonder how I could manage a life without them. That is why I continue to seek as much advice as possible from the specialists and constantly do my own research to seek out alternatives or advancements in this field.

That is why I am so happy I have been fortunate enough to meet this new pain specialist. After 25 years of consulting with these types of doctors, I have never met one with as much empathy as this one. He has his own story, his own experience - which is why he is able to truly understand what each day is like for someone like me. He is the kindest, most understanding doctor that has ever treated me and I finally feel blessed to have him by my side through this journey.

The medication makes me feel like I'm still the person I want to be, still the person my family and friends love. Most importantly, it drowns out my reality for just a few short hours so I can actually be all those things I crave. Then the fear sets in as I'm so acutely aware I'm on a slippery path again, one where the only way is down and it's not a matter of if that will happen but when.

When I was 14 I injured my knee playing basketball. Sports were my life and I was devastated that I would be on the sidelines whilst I recovered. Initially it appeared to be nothing more than a simple patella dislocation which should have meant four weeks in a cast and some physiotherapy.

After the cast was removed, it quickly became obvious that my knee had not healed. I was sent to see a surgeon and after some scans he booked me in for my first operation on my knee. I was assured even though it was a large procedure which would require a long incision and eight days in hospital that I should be back to life as normal within the year.

That was my first real experience with opioids. I remember waking up after the operation and feeling alright. However as the general

anaesthetic began to wear off and the pain set in, my muscles tightened and my body began to pound. I was given an injection of pain relief. Instantly my body started to feel warm and tingly and the pain went away completely. I couldn't believe how well it worked. In my young mind though, I didn't see it as anything other than a quick solution to help the pain. I had no idea what role they would play in my life to come.

Although the injections helped me through the initial days after my operation, as soon as I felt I could cope without them, I stopped taking them, even though I was still being offered them. I was on a mission to recover as quickly as possible. All I wanted to do was get home, get on with my physiotherapy and start making my return to sport.

Within weeks of my surgery it became very clear that not only had it been unsuccessful but things were a lot more serious than any of us could have imagined.

I was only 14, very young and full of positivity that if I just kept doing as the doctors told me to do, I would move past this accident and my life could return to normal.

I didn't recover though and my patella would continually slide out of place. We sort out the best surgeons around and slowly my life took a drastic turn that no one saw coming. I spent years in absolute denial over my situation. I only allowed my mind to believe this was temporary and that soon it would be over. It took me over 20 years to come to the realization that this wasn't going away. I couldn't deny it anymore and I had to find a way to live with it.

Over the next 15 years I had well over 25 major operations. At times my leg was so bad I couldn't put any weight even on my little toe as my entire leg would give out. Surgeons reconstructed my leg from all of my muscles in my thigh to positions of bones throughout my shin and knee. All of the muscles in my thigh were in the wrong position and after so many failed attempts and bad decisions by surgeons I was left with tendons, muscles and ligaments in the wrong places through-out my whole leg.

Even with all the operations and specialists on board, nothing was working. They held meeting with a panel of members full of specialists and physiotherapists to discuss my situation and the best way to handle it. When I would hear that a group of five to seven doctors all agreed they had a solution of course I thought things would be OK. They knew what they were doing and I put my complete and utter trust in them.

My life revolved around hospital stays, wheelchairs, crutches, physio and severe chronic and acute pain. My family was incredibly supportive and even though I was taken to see the 'best' surgeons all

over Australia and even the United States, we still struggled to find an answer to keeping my knee stable.

Nobody seemed to have an answer. The amount of surgeons that were so 'gun-ho' that they could be the one to fix my knee and came up with operations to stabilize my leg was unbelievable. Instead of being honest and upfront that they were in over their heads and not completely sure of the answer, it seemed, their ego was more important and thus I was a guinea pig for a lot of procedures that not only failed to fix the problem but quite often added to it.

When you are in pain to the point of not being able to think straight, the thought of another hour of the agony can be so overwhelming that it is next to impossible not to get your hopes up each time someone tells you they have the answer to the problem. It is impossible not to feel some type of hope, even after all of the failed attempts. If I didn't have hope, I would have nothing.

Up until about 8 years ago, I somehow managed to only use the pain medications offered to me during hospital stays and just after surgery. I didn't like the way they made me feel and even though I had had so many procedures I had been able to avoid any dependency on medications.

When I was about 29, I had to have another total knee reconstruction. The surgery seemed to go smoothly, however it was still too early days to know if it had actually worked or not.

I was about eight weeks into my recovery when I visited the surgeon for a post op appointment and to have some bandages removed. During the appointment he noticed that the last centimetre of my scar looked a little infected. He didn't seem alarmed and put me on some oral antibiotics. Seeing as he didn't seem too worried, I didn't think too much about it and my then husband and I got on with our house hunting that day.

At about 8pm that night I started to feel like I had a small fever and just didn't feel very well. We looked at my knee (which was still bandaged up) and we noticed that I had a small red line appearing from my knee heading up my thigh. I knew this was a sign of what could be a bad infection and so we headed to the local hospital.

We were kept waiting for hours at the hospital, even though the red line was getting darker and longer by the minute, we were kept waiting. Finally at midnight one of the triage nurses removed the bandage and we were horrified to see that my scar was beginning to split open and my knee was starting to swell unbelievably. She suggested we head straight to the hospital my surgeon worked at.

We arrived there at 2am. I was pretty shocked when I was informed that not only was my surgeon now away on holiday but that they

didn't have any spare beds and I was sent to the waiting area until someone was free to see me. Nobody was actually taking the time to listen or look at my leg and take things seriously.

I sat in that waiting room from 2am until 5pm the next day. I didn't sleep and the pain was beyond anything I had ever experienced. My husband spent the whole day begging someone to come and look at me and was told so many times we simply had to wait as they were too busy.

When blood started literally pouring down my leg and through the 4 crepe bandages on my leg we removed it ourselves and I got the shock of my life to see that more than half of my scar had now opened up and the wound was so deep I could see bone. It was continuing to split open in front of our eyes.

My husband demanded a doctor come and see me immediately and wouldn't leave the nurses station until a doctor was brought down to the waiting area to see me. The lack of instant treatment, I so clearly had needed had been pushed to the side was infuriating.

A doctor eventually came to the waiting room and was utterly horrified to find me in that state.

Within minutes I was being prepped for surgery to have my knee washed out to try and remove the infection. It was determined pretty quickly I had a severe golden staph infection. My infection level was well over 200 hundred when it should have been below 10.

That night I had surgery to wash out my leg but because the infection was so severe they had to leave my entire scar wide open so that they could continue to put me under a general anaesthetic every couple days to wash it out.

I wasn't allowed to get out of bed, not even to go to the bathroom. I developed a bed sore on my heel from not moving that also became deeply infected. I was at an extremely high risk of losing my leg by this point. When you have metal in your body it makes infections even more serious and a lot harder to treat.

The pain was above and beyond anything I had experienced previously. I was written up for four hourly pethidine injections. Within days, my entire thought process had begun to revolve around those injections. The dosage was high and within moments I would have a warm sensation take over my body and the pain would melt away.

These injections had a short life though and within two hours of having it, I was already feeling desperate for my next one. They were the only thing making the entire experience manageable. It got to the point that I would set the alarm on my phone 10 minutes before I

was due to notify the nurses and make sure they would be ready to administer it the second I was allowed my next shot.

I spent over a month in hospital having these wash out surgeries every couple days and I was on IV antibiotics and these injections the entire time. The fear every day of what was going to happen and waiting to see if they could save my leg was horrific.

At the time it didn't even occur to me that I was developing a serious dependency on the medication. I just figured that once my knee had healed and the surgeries stopped, the pain would subside enough for me to go back to life as usual.

It was so depressing spending that much time in hospital (keeping in mind I had only just gotten out after spending a couple weeks in there for the actual knee operation I had that started all of this) and it was hard to see the light at the end of the tunnel. After so many years of fighting just to keep my leg stable I couldn't believe now I was fighting such a serious, life threatening infection.

Eventually I was released from hospital and again it wasn't long before we realized that the operation had once again been unsuccessful. Due to so many surgeries and the instability in my leg, I developed serious chronic pain.

Each day got worse and once again the agony has driven me back to this specialist, searching and demanding that he set me free from this hell.

The pain that is so present feels like someone is clawing their fingernails down a blackboard in my head and I can't escape the noise no matter what I do. I just want to turn it off, even if only for a few minutes to let my body calm down physically and emotionally. No meditation or distraction of any kind has ever offered me the quiet, only the pain medication.

It's not just any pain medication though, it's opioids. The type of drug that is destroying lives and is so sort after on the streets where it sells for fifteen times its value. Yet because a doctor writes a script for me and it's not illegal, it's very easy to convince myself I am not like any of those people.

I'm not a druggie. Denial. That's the easiest way to separate myself from those people and those situations. It's a choice they make for some stupid high I tell myself, I am different because I don't feel like I have any other option, so this is the choice I make for myself.

One thing I have always known to be true is that I would never take it, if I didn't desperately need it to help the pain subside and make my life more tolerable. *They* are the lucky ones I think to myself as I start

the drive to the chemist, they could stop at any time and their life would only benefit from it. On the other hand, if I stop I won't feel better or healthier, I'll be lost, on the edge and unable to quieten the background noise.

I don't drink alcohol – I haven't had a glass of wine or anything else since I was about 20. I've also never allowed myself to take the sideways step of reaching for 'street drugs' to find some relief.

I've had more offers for recreational drugs than you could imagine. Some days I wish I could just go out with my friends and have a few drinks and enjoy a laugh with them. I know it is taking a risk to mix the medication I am on with alcohol and so I never allow myself to fall into that trap, no matter how enticing it can be some days.

They use to torture prisoners of war by not allowing them to sleep for days on end until their mind and bodies were ready to collapse and give up. That's what life with chronic pain feels like. Torture. No sleep, the feeling of someone bashing my knee with a hammer again and again, never stopping, never allowing me a moment to catch my breath and feel human.

After a couple of days of no sleep, mixed with the pain, you find yourself in a very vicious cycle that is devastatingly hard to break. Your body needs a chance to rest and shut off so it can recover but the pain doesn't allow you to fall asleep no matter how exhausted you are. Concentration suffers and mentally you feel like you hit a wall where you will literally do anything to put an end to the cycle.

I had to have another operation just a few months ago to fix a hole in my leg. There was the small possibility that with the hole gone and new muscle there in place, my pain might reduce a little but it was not the motive for the surgery. My leg was severely disfigured and the lack of muscle prevented me from doing any kind of physio or other treatments to gain some strength.

I put off this surgery for over two years because I was so scared of the ramifications. The incision at 40cm leaves for a lot of nerves to be cut through and the risk of them being damaged in the process felt too high.

I also now had my young daughter to consider and the idea of being away from her while I was in hospital was scary and upsetting and we knew the recovery period would be long and tedious. It was a big decision and one I spent a long time debating back and forth with myself and others.

I'm fortunate to have incredible parents that always step up to the plate and do anything in the world they can to support me and my daughter. After mulling over this procedure for two years I came to the conclusion that I had to have it. Specialists had been helping me

manage my situation with the medication but there was no light at the end of the tunnel or hope of change unless I became active again and did something to hopefully improve things a little. At the time I figured if it improved things by five or ten percent it would be worth it.

So once again I was booked in for the enormous surgery. It took nearly four hours to complete and I spent a good week in hospital before I was able to return home. The first three weeks past and my recovery looked healthy. The muscle had attached and so far everything had been deemed successful.

One afternoon I got a shooting pain down my leg that was so severe it took the air right out of my lungs. I thought it would disappear in a few moments - suddenly it felt like somebody was lighting a match and pressing it against my leg, over and over again. I would have a fiery pain that would last for 20 to 30 seconds but before it even subsided it would start up again in another spot.

If I so much as brushed my leg in the wrong spot it would send a bolt of pain through my body, so strong that I often vomit within a minute or two. One day I was walking to get the mail and it started to drizzle. A drop of rain landed in the 'wrong' spot on my leg setting off a bolt of excruciating pain that left me winded. I spent the rest of the afternoon vomiting. All because a drop of rain had landed on the *wrong* spot. I can't believe my life has come to this.

The surgeon knew it was nerve damage but hoped it would die down quickly. The longer it continued, the more severe the damage and therefore the less likely it was to dissipate.

Days soon turned into weeks and weeks into months. I can't wear pants as I can't tolerate anything touching my leg and setting off another bolt. It feels like you are being electrocuted. While that might not seem like a big deal, it certainly is in the middle of winter when you are confined to shorts and unable to even wrap a blanket around you.

Seven months after that surgery the nerve pain has taken over my life. I thought living with chronic pain was bad. Living with chronic pain and nerve damage is beyond comprehension.

I had worked so hard to get a good degree from university and had spent years working on my career and yet as each day passed and my knee got worse I felt such a devastating loss for all of the things I can no longer do. No matter how hard I was willing to work at things and make something of myself, my pain keeps getting in the way.

I've now had four nerve treatments (procedures) to try and block the nerve pain but everything has been unsuccessful so far. I've met with just about every specialist available and each visit leaves me feeling more and more hopeless.

The next 'answer' available to me is to have a little machine inserted into my spine. This will have leads down to the nerves in my knee in the hope that they can be blocked. It is major surgery on my back, right next to my spine. Every time the batteries die it would mean another operation to have them changed. Every time something needed to be modified or checked, it would mean surgery next to my spine.

After what I have experienced with my knee and now at 38 years of age and well over 30 operations under my belt, the thought of having this device implanted into my body is terrifying. Surgery is what got me into this mess in the first place and to introduce having more of it - on such a crucial and vital part of my body just does not seem like a smart move at this point. Especially when I know success rates are low and I have met people who have similar devices and pumps in their backs and it only seems to add to the stress of the situation. They can't sit comfortably in a car or seat and now their entire life now not only revolves around their pain but this device in their body.

So I am choosing to hold off on this 'answer' being offered to me and see what the next year or two of science and research comes up with. I have regretted many of the operations I have had but this last one feel like the biggest mistake I have ever made. I was right when I put it off for all of that time, fearing the risks involved but I felt like I had reached a position where I had no choice if I wanted a chance to move forward. Now I have taken 10 steps back. I would do anything to turn back the clock but of course I can't.

I pull up to the stop light just a few blocks from the chemist. I'm almost there. I calculate that if I give them twenty minutes to put my script together and then race back to my car to take a couple tablets, it will be 40 minutes before my shoulders will drop with the feeling of the weight of the world taken off them and I will be feeling like 'me' again. That's not too long, I tell myself, you are close now.

With that excitement the fear grips me even tighter again. Another week at least now of being stuck on these drugs that will rule my life. Suddenly my days are dictated by how many hours in the day compared to how many tablets I have. I have a big week ahead of me and I intend on conquering everything on my list of things to do. I berate myself for all the times I've allowed myself to have a couple more each day, feeling I really needed it, only to be left short for the last two days before the next script will be in my clasp. I promise myself I won't do that again and maybe, just maybe this time I'll even take less than the amount I've been offered.

This isn't the part I fear so deeply though. The fear is about knowing with each tablet I take, my body will become more tolerant and within weeks I'll be having to double my dose. I've been here before, a few times now and suffered through the extraordinary experience of

coming off everything to allow my body to recover from months or years of taking these heavy drugs. It's a choice I make because the fear of being on these forever is too daunting. The withdrawal process is like you see in the movies, only a film cannot make anyone truly understand what it feels like. The anxiety and stress involved with these medications and the fear of how your body will cope without them, can often be worse than the actual pain itself. It is a cruel and unfair added pressure to an already debilitating situation.

A specialist told me once that it is like your body is grieving the death of something. Something so powerful and meaningful to it that your body simply falls apart, unable to cope with the prospect of not having the drugs. The last time wasn't just a few horrible weeks for me however it was 3 months of pure and utter hell. As the medication left my spinal fluid it sent my body into a rage of spasms landing me in hospital almost daily. Doctors informed me that after a few hours of each spasm my body was so exhausted it was the equivalent of me running a marathon. I wasn't doing just one marathon, I was doing a daily one for three months.

I promise myself, I will no longer touch that particular drug and I will never let myself fall so low that I have to endure that process again. This is a daily battle, will my will power be the victor or will my brain - the most powerful tool I have, be too weakened by the pain? It's too easy to convince myself that that's not something I need to care about right now, it's only possible to care about the fact that for the rest of the day I won't have the pain that has crippled my life. Tomorrow is a new day and another 24 hours that I will have to somehow figure out how I will get through. It is too easy to get stuck in only focusing on the *now*, not five hours from now or tomorrow.

This is what my life has become. Some mornings it takes me 20 minutes to be able to get out of bed. I do my best each day to balance life as a mother and life as a person with chronic pain.

I was only fourteen when I injured my knee which led to the 30 plus operations over the next twenty years. Sport was my life, I was passionate about it and I was good at it. For years I fooled myself into believing this was a temporary situation and the next surgery would be the one that fixed everything. Denial is the only thing that got me through those first few years.

Then before I even realized it had happened, I was battling just to find something or someone that could stabilise my leg enough to walk. 10 years past where I could barely manage stairs and function was now the only goal. The choices I made to achieve that slowly left me with severe nerve damage and the loss of my entire VMO.

Chronic pain was inevitable and I had to force myself to face my new reality, a life with deep, pounding pain that I can never escape.

Even these drugs don't take it away, they simply dull it enough to allow me to do what I need to do to get through the hours. There is no room in there for following a lot of my dreams that require a fully functioning, healthy body. I've had to make new dreams and build a life around my disability.

Luckily new life is powerful enough to breathe life back into me. I have my young daughter now and everyday her laugh inspires me to keep going, keep putting up with the pain and most importantly to keep laughing with her. I want to make her proud. I want to teach her that no matter how hard life can be, no matter how many dead ends you may meet, you have to keep trying. You have to stay positive and keep looking forward.

I am writing a novel that will soon be published. It has taken me so long to write it. A simple paragraph that should take only a couple minutes can easily turn into hours as it is just so hard to concentrate with the pain. It is a goal I will achieve, I will show my daughter that you can still be who you want to be in life, you might just have to take a few different roads to get there.

As it does each day, my mind always shifts back to my daughter and how she is my entire world.

I enter the chemist in a new frame of mind, not excitement for the drugs, not fear for the future but happiness as I think about how lucky I am to have her and how she needs me to stay determined to stay on top of this every day and never give up hope that things will improve. I pull her in for a cuddle and kiss her head, silently thanking her for giving me everything to live for.