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Grampians Regional Palliative Care Team

ORGAN TRANSPLANT, DIALYSIS AND PALLIATIVE CARE
A PERSONAL ACCOUNT

As part of the Grampians Regional Palliative Care Virtual Conference on May 13-14 one of the featured topics is on Organ and Tissue Donation and the role of palliative care within this patient cohort. Dialysis is a life support system for renal patients who are on a palliative pathway unless they receive a successful kidney transplant. This is the personal story of Grant who has lived through two failed kidney transplants, peritoneal and current haemodialysis and a prolonged hospital admission which he was not expected to survive. His account gives us an inspirational insight into the encounters he has dealt with throughout his young life dealing with renal disease.

G'day, I'm Grant, I've been asked to share some of my story with you about tissue donation, palliative care and living with renal disease. To most people I might look like a normal 27 year old… well maybe not quite 27. My young appearance is caused by kidney disease, something I've been living with my whole life. It means my kidney function is pretty much non-existent. My 'young' appearance makes simple things like filling up my car with petrol and a short trip to the supermarket to buy "party supplies" an interesting experience. Once the petrol pump got cut off at the servo because the attendant thought I was a joy rider stealing a car. Dinner with friends can be entertaining when waiters just assume I ordered the kids size meal.

As a kid I always considered myself lucky, I'm not sure if I was born an optimist or if the supportive positive vibes of my mum and the small rural community I lived in rubbed off on me too much. Although I started showing signs of kidney failure when I was 18 months old my parents noticed something wasn't quite right and a 3 hour ambulance trip to the Royal Children's Hospital diagnosed Nephrotic Syndrome. It is a condition that causes the kidneys to leak large amounts of protein into the urine, causing a range of problems including swelling of the body tissues and increased risk of catching infections. (www.nhs.uk/conditions/nephrotic syndrome in children). It wasn't until I was a little older that I realised my life wasn't as 'normal' as I thought. My condition was managed with medication until I was around 6 years old, when my kidneys then started to fail completely and I needed a transplant. Mum being Mum naturally didn't hesitate in offering me one of her kidneys.

My dad, who struggled with mental illness, also wanted to donate a kidney to me and began to become jealous of mum. Unfortunately while I was preparing for a transplant this led to the violent murder of mum, and I lost both my parents. My older brother Ashton and I luckily moved into a lovely foster family… but the doctors thought that with the stress of everything it might be too much for me to receive a transplant at this time! Instead I started on peritoneal dialysis overnight. Thankfully this treatment option allowed me to somewhat manage my condition at home with the help of my older brother, who even though we lived with a foster family, took on a fatherly role and became my main carer at just 16 years of age. Peritoneal dialysis gave me the flexibility to have the day free like many other young people with a chronic illness. I was able to go to school, develop friendships, and build my social skills which has helped me deal with the challenges of living with a chronic illness. I was also able to avoid hospitals as much as possible, although sometimes home was like a hospital with our storeroom full of dialysis supplies and medical equipment.

Whilst having the day free was good, it was annoying having to go to bed right on time, to have my dialysis and be able to get up for school in the morning. I couldn't bargain my way out of another hour to stay up and watch my favorite tv show!! During my early schooling I was fortunate enough to have a great group of friends and teachers who understood my needs, but who also didn't define me by my kidney disease. After 7 years on Peritoneal Dialysis I received a kidney transplant off the waiting list; it went into shock and never worked. The following year, age 13, I received a second transplant which worked for four months but then rejected. This was a lot for my body to go through at the time and emotionally was very hard to accept. But with help and support from family and friends I managed to recover reasonably well and continue with life. At the age of 16 when I was close to finishing Year 10, I became very unwell and was sent to the Royal Children's Hospital. Because I had been on peritoneal dialysis for so long, it had stopped working and began to cause complications, such as an obstructed bowel, multiple infections and even phenomena. I also lost a lot of weight. I was managed under the palliative care team and not expected to ever leave hospital. It was a difficult and frustrating time, but after 9 months I somehow gained enough strength and was discharged from hospital and transitioned to haemodialysis.

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The palliative care team did an extraordinary job in coordinating and collaborating the many health care teams involved in my care. They also provided practical support to my brother and I which made dealing with my illness a little more bearable. This included respite days where I would leave the hospital with a nurse so both my brother and I could have a "break". When I was at my sickest point I was even able to go home with the help of the palliative care team who made sure home was a safe and suitable setting for me to still get the care and treatment I needed in the comfort of my own home.

Thankfully I made an unexpected full recovery. I quite often credit a portion of my ability to recover to the wonderful palliative care team who managed to make such a challenging and emotionally draining time so much easier to deal with and gave me the best quality of life and care possible, considering my debilitating illness at the time.

Due to the lengthy hospital stay during year 11 and 12, my education was impacted. While all my friends were worrying about exam results and what they wanted to study, I was stuck in hospital stressing out about my blood test results and wondering if would ever be able to study at all. I tried to return to school and attempted Year 11 for a while, but my school friends were ahead of me in Year 12, and after what I had been through I just couldn't focus. I am yet to complete my VCE and am not sure I will.

Right now I currently receive dialysis treatment 3 times a week in hospital for 4 hours at a time. That's just 12 hours of artificial kidney function a week. Which isn't a lot compared to people with healthy kidneys who generally have function 24/7. Just like most 20ish year olds I like to socialize and have a few drinks on weekends and by Mondays I'm usually feeling a little hung-over and sorry for myself… But for me these hangovers are not by choice or from having had a crazy night out and drinking too much alcohol. It's because my body loses its ability to excrete any fluid naturally. This means without functioning kidneys I never have to pee (which comes in handy during long car trips or movies.) But the down side to this is that by not having any way to remove fluid I need to restrict the amount of fluid I drink in between dialysis sessions. If I don't manage it carefully my body is usually feeling pretty full and crappy from both toxins and fluid.

After leaving school, studying and finding a job are hard enough for any young person, but with kidney failure and dialysis it is twice as hard. Finding an employer that can understand and is okay with my somewhat unstable health was challenging. I've been lucky enough to find employment with Kidney Health Australia, an organization that has supported me tremendously since a very young age. I attended my first Kidney Health Australia Kids Camp at the age of 6. I have been attending ever since and am now employed to assist other kids going through the same struggles I did when I was younger. Growing up, you don't meet many kids with kidney disease. It can be an isolating journey and for many kids it's their one chance to feel normal. I have made life-long friends through these Camps and I am entirely grateful to Kidney Health Australia for this program.

A couple of years ago I also enjoyed a holiday in Anglesea, utilizing the services of Kidney Health Australia's Big Red Kidney Bus. I was able to receive the dialysis I needed to stay alive, all whilst exploring this beautiful coastal area. It was so nice to feel such a sense of freedom and have a break from the hospital. I am so grateful for Kidney Health Australia and the many avenues they have provided for people like me to receive support.

Although a lot of people often ask me how do I do it or how do I stay positive I think the biggest thing that gets me through is the fact that I am lucky and privileged enough to have been surrounded by such awesome support networks growing up; via my local community, friends family and healthcare team. Although I know that kidney disease doesn't discriminate - it affects young and old, male and female. I've had my lows, but many out there have had much worse.

Many thanks to Grant for sharing his experiences. If you are interested in attending the virtual conference please go to our website www.grpct.com.au

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