

Speech Short bio

BIO

Damien Thompson 31 years young, still 23 at heart, born and bred in NQ. Lived and worked in Townsville for my parents business Bayswater Road Radiators. I attended Ryan Catholic College yr1 - yr12. I have 3 brothers I'm the second oldest. My hobbies include pretty much anything outdoors but most of all fishing. I'm committed to helping the future funding towards research into GVHD and rejection among organ transplant patients and In the past I've managed to raise money for the leukaemia foundation light the night events and privately organised events with the help of family for GVHD research.

Entrance

I was worried as I was coming up here because before this event because MJ was telling me she'd kick things off by telling a joke then handed over to me

INTRODUCTION

Hi everyone, its really good to be given the opportunity to speak today thankyou for taking the time to attend, I know this means a great deal to a lot of people myself included. I've had much encouragement of late to share my story so I am going to do my best to share with you my journey.

In preparation for this I found myself filled with anxiety and it had me thinking. What am I so anxious about? I've survived the last 8 years what is this really all about. So I'd heard the common saying 'picture everybody in the room naked' before but that wasn't doing it for me so I added a little detail in to the mix and found myself content. That is to say not only are you all naked right now but you are in the middle of Antarctica. I promise I won't peek.

Before I begin I'll start by saying I am really thankful of the Leukaemia Foundation team and its efforts to always find a way to help with the hard struggle of my treatment. It's a great community of people forever willing to help, from transport needs, organised events, comfortable surroundings, general day to day activities, exercise programs and more. I've stayed in many locations starting 8 years ago and have noticed a big improvement over that period and can honestly say the changes made so far have improved the living experience in terms of comfort by a huge amount. That's a very important thing when you are away from home. So well done and j to you guys.

My aim today is to share my experiences with GVHD and hopefully give some perspective on the disease by sharing some of what I've learned overtime.

70% of BMT patients will get GVHD. GVHD is something all leukaemia patients are faced with after having a BMT. It's a

crippling often life threatening disease as a result of the cure. Not a lot is known about it therefore treatment is very broad and harsh often causing enormous damage to the patient. I have a word for it but its definitely not appropriate to share. It's often thought the hardest part to treatment is the Chemo, I beg to differ.

So in my experience more needs to be done about this terrible disease.

Unfortunately I've met some wonderful people succumb to this and its harsh ways, It's not a good sight. It's nature is to destroy everything in your body, think of that for a minute and the current treatments require a broad hit of mass immunosuppression and toxic medications to cover all areas and with that there is very limited options available so combination therapy, very broad based is the first and last line of d Even chemotherapy has got so advanced in targeting the Cancer yet a lot of GVHD remains an unknown. Not only does GVHD effect cancer patients but its cousin 'rejection' you could say plays a simular role in organ transplant recipients and so if we can start with understanding GVHD we will be well on the

way to solving rejection among transplant patients as a whole. Really an enormous leap in healthcare. Progress has been made at QIMR medical research in Queensland right here at home.

GVHD RESEARCH

Up until recently Professor Geoff Hill was leading research and has been responsible for setting a solid foundation in this field, now headed by Dr Siok Tay leading the team forward continues to progress. Such talented individuals dedicate their lives working long hours in order to find a cure QIMR Berghofer feels like a close family like community.

More needs to be done but that all starts with us. It's my dream to see more fund raising for this and the inspiration behind this is that I'd like to have kids one day (hopefully soon) and the last thing I want for their future and those I am close to is to experience something I have.

Moving on rather than tell a story I have put together events in time to reflect upon, hopefully it can give you some insight into a GVHD patients journey.

Up until recently I'd imagine my last 8 years to be one boring adventure, little did I know that it actually has a positive effect on people so coming here today was a no brainer. I'm happy to help where I can especially when it comes to awareness and emptying peoples wallets. This is a personal look into my life before during and after illness.

Facial expression, clean slow words, look up engage

The beginning

Home work life

I was a busy kid borderline allergic to indoor activities my days were filled either fishing or playing sports, mainly soccer, finding myself travelling Queensland representing teams training up to 5 days a week. As I grew older I found myself everywhere all the time, full of enthusiasm and had the energy to back it. I am very fortunate to have many childhood friends I still see regularly these days.

School life was very casual. We had a good bond with teachers and a tight knit community of classmates. I was interested in PE, Science and Drafting or Architecture classes mostly. The benefit of performing well in PE was that you had days away from school competing in track n field so I trained hard.

So growing up playing sports is the theme of my life, I was fit very active and definitely couldn't stand still. I found it hard to sit on a couch in fact I couldn't think of anything worse. I remember going to the movies on a date and falling asleep (that relationship didn't last long)

Our school grad was 2004, I was faced with 2 directions, 1 study business or 2 study architecture. At that time the family business was expanding so naturally I put things on hold to lend a hand. I found myself more involved with the

company, putting in lots of hours and demanding work yet still I'd make soccer training and gym during the week.

I'm 21 at this stage and after some travelling and life experience I found myself at that point in my life where it was time to have clear direction so I was determined to pursue a career something that would take me around the world, a lot of this had to do with an back injury in which I herniated a disc in my lumbar spine from heavy lifting and twisting at work. So I'm 23 now and just started a new job at Cooldrive and looking forward to the future, Between my usual activities gym, fishing, camping, riding dirt bikes, travelling socialising, working hard, managing relationships I still had energy to burn. My life was great.

Healthy pics

Along the way I'd discovered this creeping pain slowly throbbing from time to time in my lower back. 3 months into my new job and within a week that pain had intensified and progressed up my spine. I'd had steroid injection into my disc to try calm the sciatica I was experiencing but in doing so created a huge haematoma in my lower back making things worse. Elaborate....the scene...getting out of my chair and falling

It got to the point I found myself in the shower on an early Sunday morning with nothing but hot water running trying to numb the pain. When it was obvious that wasn't working I tried to sneak out the door and to the hospital as not to worry anyone (this was 2am in the morning)

Thankfully with the benefit of hindsight I made enough noise to wake my gf at the time and she rushed me to Emergency. By this time the pain was so severe I found it hard to breath and was shaking uncontrollably. After a quick blood test I was hit with a whopping dose of morphine and sent to Oncology. WELCOME YOU HAVE LEUKAEMIA! This happened to fall right on father's day so it seems I am quite the party pooper.

Cancer A new way of life

Introduction into the treatment process

Journey highs and lows

Rehab, recovery

In my hospital room was utter chaos with family and friends all wanting to visit, it turns out I was in a bad state... elaborate the scene...Hip biopsy, fevers covering the bed

Thankfully soon after I was under control. From there I met the team of Doctors and nurses from the TGH Oncology unit and couldn't be more relived to be in their hands. We had a plan and much assurance I was in the best of care. I suspect a lot of people here today have not had a stay overnight in an oncology ward but let me tell you it is an unpleasant place to be even when your not sick.

After 3 months of intense chemotherapy including regular injections of chemo into the spine Elaborate the scene...holding onto the bed, not sleeping 4 days...

After that I was in remission and sent straight to Brisbane for a BMT. The Leukaemia Foundation organised a room for me and my family straight into the old units there at Southbank where the new Mater Childrens Hospital is now. I was told that was by far the best option for me. The dangers faced with a BMT are GVHD but because my brother was a match 8/8 It was assumed I'd be alright. Moving on I'd been admitted and had my irradiation and knockout chemo and the day was day 0 March 15 2011 transplant infusion day. After a quick celebration and 3 1/2 weeks bedbound on TPN or bag feed, I'd recovered enough strength to go home. What a feeling. I could see the end, I had done all the hard work now I could concentrate on rehab at home and slowly recover. I could remember the escape, I felt like I was breaking out of prison thinking it only gets better from here.

GVHD

The unknown

How wrong I was, not long after I had experienced a skin rash and severe diarrhea. This was intense and fast moving acute GVHD. I remember thinking this is a whole other game. My GVHD had activated CMV a sometimes fatal virus especially in highly immunocompromised people. Somedays I could barely walk from pain and burning feet. Elaborate the scene... walking to and from mater and village

Thankfully after a switch in medications and some sleepless night's I started to stabilise. A few months pass and by this time I was well enough to continue follow up treatment at home, Townsville. I was stoked to finally be going home to friends and family and looking forward to getting back on my feet and starting a new life.

About 11 months post transplant now I was home settling in. The 12 month immunosuppression therapy was due to end freeing me for risk of infection, I was feeling better than ever, having regular checkups, managing a rehabilitation program and starting part time work I really was excited for the future. I'd beaten Cancer, I'd beaten GVHD time to plan a new direction in life.

And then...

Like everything at once I got a call from a close mate I'd met in hospital Chris he was from Mt Isa and was going through the same thing post BMT telling me devastating news, not long after another call from another mate I'd made in hospital Dale from Cairns all with the same condition, telling me devistating news. As we were all fellow Leukaemia patients of the same age we had formed a tight bond so I felt pretty vulnerable, trying to keep myself together I continued on without them. Elaborate the scene BMT into battle...

Now working back at my old job getting into the groove I started to feel lethargic, short of breath, tired all the time. I'd raised this issue with my team and after some serious

head scratching it was determined the GVHD had returned. You've got to be kidding. Firstly in the liver, then the eyes then the lungs.

With another Christmas in hospital trying desperately to control the GVHD unsuccessfully a decision was made, I needed further investigation and sent back to Brisbane. In disbelief I referred to my old methods of handling this situation and adapted quite fast. I'd hope after some time we'd manage this and I couldn't get back to things, back to life. That was 2012. Things didn't get better in fact gradually worsened with such debilitating symptoms. After many visits to Emergency, plenty of long stays in hospital, dodging infection taking many different medications my future was uncertain, my life never the same. As you do you move on, do your best, be your best and hope for the best.

Elaborate the scene...locking yourself away... In 2016 I had deteriorated to a point where not only couldn't I breath but I couldn't walk, the femoral heads on my hips were collapsing I was falling apart from all the steroid use, CHECKMATE.

I needed new lungs asap. After the amazing efforts of my Doctors from the Royal Brisbane I was accepted for lung transplant from the Prince Charles team and registered on the waiting list.

After 2 false alarms I was waiting for third time lucky. Just on 10 months and I got the call, 'get in here you have new lungs'. Excited yet slightly anxious arriving to hospital I was quickly prepped and rolled into the surgery

room and the next thing I remember is waking up with tubes hanging everywhere. The day was June 14 2017

Lung Transplant post surgery

Hip replacements

Optimism and happy thoughts guided me through hoping this was the last of it. After 3 weeks stay I was able to go home and start slowly rehabilitating albeit thinking this feels strange. After addressing the issue was assured it was surgical related and will all settle. Time would tell otherwise and as it happens I stand here today I continue to struggle with GVHD and the serious effects it causes, in my case severe chronic fungal infection effecting highly immunocompromised people. No you cant catch it even if you kissed me (singles girls in the audience take note). Other daily struggles related are burning eyes sensitive to light leaving my sight vulnerable, worn out hips (so I've had both hips replaced now) and many other little things skin and nerve related conditions like vertigo so if you notice me stumbling around No I'm not drunk (try telling this to any bar patron) So this leaves me where I am today. GVHD is a full time job it is debilitating, it effects so many and is so unfamiliar. The amount of times I've had trying to explain to people even in the health industry what GVHD it blows me away and that's why I'm desperate to help understand it because without GVHD I like many others would have a bright long future ahead. It's very important to better understand GVHD as a whole. We know what it can do but by then most of the damage is done and so in

understanding the condition it fundamentally changes the way we treat patients.

Without such a great team of Doctors from Ian Irving in Townsville General Oncology unit at the time to James Morton here at the Mater Hospital onto my thoracic Professor Rob Boots all playing a huge role in getting me here today now in the capable hand of the Prince Charles Lung transplant team under Dr Peter Hopkins and Dan Chambers so thankyou to them and thankyou to our great healthcare system.

Admissions

My lung transplant was supposed to be this new beginning that I pegged all my hope and faith towards being a success. I remember looking forward to the operation, with no feeling other than optimism and happiness. On the day I got the call everything happened so quick. 'Damo get in here this is it' says the lung transplant co coordinator. As I were and with the clothes I was in headed straight for the hospital calling those close family and friends on the way. I arrived and am prepped and briefed and before I know it I'm wheeling into the surgery room. Everything I'd worked for, the sacrifices made, the pain and self discipline to one day get to this point and I was here I was thinking as I drifted into unconsciousness. That was my last memory, a cold wind blowing on my head above the entry door to the room then...

After 8 hours I was lying in ICU with tubs hanging out everywhere. I started out with the usual Damo humour from the side effects of the cocktail of drugs I was on. Being the stubborn prick I am I would ask for my limits from the nurses especially the physios then set out to double that. This started great, I was pushing my limits, improving my numbers when I raised some concerns about my chest relating to the exact same symptoms prior to transplant. I had suspicions this would not go away. I remember thinking I'm only given one shot at this so I powered through putting those thoughts to the back of my mind. As time went on the problems got worse causing complications I still struggle with today, shortness of breath, tight chest and enormous pressure I can only describe as an elephant parking up and sitting on my chest. Reality set in, that new beginning was fading and fading fast. I'd thought I hit rock bottom in my life at that point, how wrong I was. It seemed all my efforts to better myself from exercising to the point of passing out on many occasions, to the total opposite. Resting, taking it easy changing diets, different therapies I constantly re evaluated myself. This eventually got the better of me, I thought 'what is the dam point of this'. It wasn't until I looked long and hard at myself in the mirror, talking to myself, something I'd done throughout the beginning on my original illness (Leukaemia) to put me back in line. Somehow pointing at myself in the way of 'you are better than this, stop waisting the time you've been given, do you realise how lucky you are' repeatedly for months until it sunk in.

It worked. It's got me to this point, made me stronger and has altered my perspective yet again on life and what's important. That's where I found Fundraising. I made a promise to myself to do everything I can in order to prevent this happening to anyone else.

Motivate

I heard a saying that really resonates with me, that is, 'You haven't started living until you've started giving'

This takes me to my next point. Getting involved... I can understand why a lot of people don't give to institutions, I get it but having said that QIMR are so different in their DNA in that its a big family all dedicated to humanity with access to the latest technology and some of the worlds best researches.

Research methods are advancing at a rapid rate allowing access to information much faster than ever before. Institutes like QIMR rely heavily on the little guy to keep their momentum for the progress they've made.

There is a new wave of fundraising and I say new because we are now investing in new ways to treat patients, a fundamental change in the research directed at studying

the body's own healing ability to detect disease and stop it without the use of toxic medications causing enormous side effects (for example cell engineering, I have more info on that if anyone is interested after the talk to come see me) So essentially instead of a broad approach to therapies we are concentrating on a more targeted approach significantly reducing the harm to the body. This should excite everyone because we are at the start of a healthcare revolution and I ask you join me in this so we can all be a part of history knowing we made a lasting change, we can help end suffering, pain and even death. I have seen it, been it and am living it. Lets do this not for me but for the future generation. My motivation is to prevent anyone else from having to go through what I and many others have. Its been said many time before but only because there is no harder truth. This could easily happen to a friend, their wife, child, your brother, sister, niece, nephew I know, I thought I would be the last person to ever get sick let alone a life threatening illness. That in itself is motivation enough to dedicate a very small portion of your time each year to fundraise or just spread the word, give a buck whatever it's so easy.

It's personal to me, I've sat by and witnessed a lot of my mates grow and mature throughout my years of poor health, I've been there for some of their weddings (if I managed to sweet talk my doctor's enough to get time away), they've started family's becoming mothers and fathers and I see the joy on their faces especially the little ones. And it would be heart breaking to me if 'god forbid'

anyone of them succumb to a life threatening illness and I had sit by and did nothing.

Everyone gives, its human. You give your mate a hand, help an old lady cross the road, reach out to the disabled, its natural. We all get gratification from that so why not give and inspire others to give and feel good I say. I dont know about anyone else but I can sleep better at night knowing I've given a dollar. I can tell you as a donor and fundraiser to both the Leukaemia foundation and QIMR they make you feel like family.

So if anyone has any ideas on how to spread the word come see me after the talk.

SUMMARY

So I get asked a lot of questions and this had me thinking. In particular to these following. Some of the most popular I've been asked are...

Lessons I've learned?

When you first wake up of a morning treat the day as your first day, Day 1. This led me to focus on the now, not what happened yesterday, not what will happen tomorrow but what is happening today. Surround yourself in a good environment. I'm big

on energy and so I find I progress further with positive people.

Accepting your illness is the first step and the hardest one. Once I accepted my illness (very important first step) I approached it like a job, the biggest job in my life. Little did I know that job was life. It's important to own your illness, wear it as a badge of honour as such to show it who's boss

Focus on here and now, what you can do not what you cant do.

Celebrate little victories, hurdles.

Always have something to look forward to. I find its very important to always have something to look forward to. It can be a small thing, days, weeks, months even years away, hold onto the thought that one day I'll do this

And get outside and talk to people. No problem is too big. Take the approach of tackling the big problems by looking at them as small ones.

An example of the day in the life of myself. I would asses my situation by involving myself in conversation with my team of Drs firstly. Secondly I'd have a goal in mind for the particular problem. It's important that I keep that goal very broad with no expectations because ultimately the point of this is to identify what worked and what didn't. I would develop a process or as I like to call 'battle plan' toward acheiving that goal (third step). Most of the time I was out

for improvement not to fix. After doing this a few times you quickly understand what is good for you and what isn't so essentially finding your strengths and weaknesses and capitalising on your strengths. I found the most important part of this is to know your weaknesses and before you know it you've created your own rule book. So work on your strengths rather than try to fix your weaknesses.

What helped me personally in my journey?

Personally I think growing up with 3 brothers. At a very young age I was taught the lessons of hard work and commitment. Early each morning my father woke up for work he'd wake us kids up with dedicated jobs to do from raking leaves, sweeping the house, taking the rubbish out, riding to the shop to get the milk are just a few. 'I'd often wonder sometimes, still cranky rubbing my sleepy eyes why I was sweeping the same place I'd swept yesterday, It was clean!'

I later understood the importance of work ethics. From that to sports, soccer mostly some kart racing and a mix of school sports like track n field. Playing sports taught me the importance of teamwork and competitiveness 2 qualities I learned well which made up the foundation of my life. Not to forget manners and respect, how to treat others, I believe to be the most important of all in which my Mum played the instrumental role. So having grown up in this environment prepares you for the hard things in life and it just so happens mine was just that.

How do I cope?

Well its all about perspective. I learned early on that it did me no good to compare myself to healthy people as clearly that wasn't the case and so I would compare myself to the worst in terms of illness and id remind myself there are people even worse. Soon you start to feel pretty good.

I'd also surround myself with positive energy a can do attitude, look at the big problems as small ones. A lot is controlling the mind telling your body what to do not have your body tell your mind what to do. And probably most importantly is to look for humour in everything. I am a natural born 'excuse me' smart arse so I didn't have many troubles.

Over and above all this I had great support and encouragement from family and friends and having been spoilt with a fantastic team of doctors and nurses made life alot easier

Reference past events, games with nurses etc

CONCLUSION

Boat pics

When the stress levels start to overflow I like to getaway and go fishing. Now fishing to me lowers the blood

pressure, clears the mind and rejuvenates the soul so you can imagine the excitement I get from it. I felt I needed a getaway a couple of weeks ago so I took off back to Townsville with a well organised trip to Hopkins reef 90km off the coast of Townsville. One of my favourite places to be. After handing the boat in for a seaworthy days prior, me and 3 mates then make the trip to Hopkins, a good 2 hours from the marina, our spirits high chatting uncomfortably the whole way out. We arrive late afternoon and after catching some fish decide to anchor off the edge of the reef and have a bbq dinner. Everything going smoothly we all decide to hit the hay and go to bed with the plan to wake up early morning and continue fishing. All is calm, everyone asleep that was 9 o'clock. And then...Show the clip

So I started to question am I lucky or unlucky?

Hi everyone thanks for coming, I'm Damien Thompson or more recently known apparently as bionic man. More on that later.

But I'm here tonight to give you some perspective from a patients point of view on the impact everyone one of you in the community have when you involve yourself in fundraising.

I'll start with the most important one and before I do I will say this. Every patient when things get tough, tougher than they think they can handle when every option seems lost or has been exhausted will always refer back to one thing, HOPE.

And that hope comes from people like you, willing to extend a hand so the guys at QIMR can work their magic. Knowing that the team are working tirelessly around the clock, dedicated to one thing, finding a cure.

Believe me I've been through the labs, spoken to many scientists often left 50 steps behind in conversation due to their level of intellect, I'm actually not convinced they are human rather some high tech cyborg robot. But on a serious note the atmosphere at QIMR is so positive, everyone is like a big family all on a mission to find a cure.

I aim to represent those who as we speak are laying in hospital beds wondering will they get to see next week.

I've been there many times but thanks to people like the team at QIMR I have managed to keep going. New drugs have been made available along my journey that's enabled me to fight another day and while that fight is still going I wake up everyday in hope of a new treatment that will eventually return me to full health and along the way inspire others out there not to give up.

Now this isn't about me it's about patients like me. Having said that I'll share my story.

So personally I've overcome a few hurdles to get here.

I was diagnosed with Leukaemia at the age of 23 and had a BMT for that. A short time later I was diagnosed with GVHD and this is when the troubles started. I'm still battling that but we haven't exactly got along very well. GVHD had destroyed my hips right at the same time it did my lungs. This made my Lung Transplant fairly tricky but we managed and I had both hips replaced not long after.

Today I find myself battling a mix of infection and rejection. I've just turned 32 and lucky for me I recently came into knowledge of a new clinical trial and this is exactly my point.

The way I see it is the more we give the faster new treatments become available the more lives we save. So be apart of something big because we are nearly there after all it is likely in some way an investment into your future health.

I'll end things there because I've heard enough of my voice. Thanks again for coming it's really important to me and I know it is to a lot of others. Enjoy the film

Last modified: 3:04 pm