Cancer Health

David de Wilde—Sharing His Story in Belgium

David de Wilde works to spread awareness of testicular cancer in Belgium.

March 29, 2021 By Justin Birckbichler

Welcome to the Band of Ballers! In this series on ABSOT, I'm turning over control to some other ballsy testicular cancer survivors and patients who have inspired me with their work in advocacy and awareness during and after their diagnosis. This month's feature is all about David de Wilde, who has worked to share his story in his home country of Belgium. Enjoy!

My story started in perhaps an atypical way. The first thing I ever noticed was my right testicle getting smaller when I was 36. However, I didn't think much of it. It's probably just something I was imagining, right? You wouldn't want a doctor feeling your balls for something that is probably just your imagination. Little did I know…

A few months later, I had a totally unrelated surgery to my eyes. But this is where my story really begins. A couple of days later, I was doing a regular testicular exam. Many years ago, I had read that such a thing is important. I didn't fully realise why, but did it nonetheless, just to be safe. So there I was, feeling my balls. There was the normal one… and the atrophied small one. There was a hard lump that felt rather substantial on that small testicle. This had me concerned, but not alarmed. After a couple of days, where it obviously didn't go away, I told my wife and my brother-in-law, with whom I also have a good relationship and can discuss such sensitive issues.

Courtesy of Justin Birckbichler

About one week after noticing the lump, I ended up all nervous in my general doctor's office.

A man, luckily, because I felt a bit strange if it would have been a woman. How do you talk to your doctor about this? Well, it appears the straightforward way is by far the best way to go. I just told him plain face I felt a hard lump on my right testicle which had me concerned. Yes, this is indeed the part where your doctor asks you to drop your pants and lie down 'comfortably.'

To be honest, he was more than understanding and surprised I was so open about it. He was not just professional, but caring. He slipped on a pair of gloves and did a physical exam of my testicles. Actually there isn't really much to it, and definitely nothing arousing, not in the slightest. He compared both testicles and actually he was the first one to actually confirm that my rightie was atrophying. He felt the hard bit in my testicle.

It was real, and not just my imagination.

This was the 10th of September 2020. After examining me, we went to sit down and had a long chat. My doctor warned me that a hardened, painless part in the testicle is a major 'red flag', a warning not to be ignored but in desperate need of further examination. He was totally honest and said this is most likely a sign of testicular cancer, but that I urgently needed an ultrasound to make the definite diagnosis. He was kind in telling me the truth. Next he picked up the phone himself to make an appointment with a urologist he trusted for the day after! Having the doctor make the call definitely expedited things. Before I left, he apologised for giving me a night, which he knew would be sleepless, and so it was. Yet still some string of hope lingered; it might be just the atrophy and nothing else.

I had never been so nervous for a doctor's appointment as the one on September 11th. I never saw a urologist before, and frankly, I did still feel shy about showing, and having examined, my important bits to a doctor. Waiting in the doctors waiting room, all alone because of COVID-19, is just plain hell! The urologist finally came to get me and after reading my doctors letter, he immediately took me along to do the ultrasound.

Once again, I dropped my pants for a stranger.

Although normally I'm not shy, still, in a doctor's office, this feels so different. He examined my testicles before doing the ultrasound, which honestly is really not a big deal at all. Now this is where the emotional rollercoaster really started.

The picture was clear, there was an obvious mass in my testicle. Even I could distinguish it as something 'wrong'. The urologist didn't beat around the bush, he told me with a plain face: "this doesn't look good, and it will have to come out."

All of a sudden it was real. There you are, you have testicular cancer and we are going to take your testicle out, chances of it being benign are extremely slim so I learned. Back in the office I called my wife and put her on speaker phone, so she could ask the questions that I was forgetting due to the shock.

He explained in detail that the orchiectomy would take place as soon as possible since this was urgent. His secretary made all the necessary appointments and there I was outside. First stop, before I could even go home, the lab because I needed to get bloodwork done for tumor markers immediately.

Courtesy of Justin Birckbichler

I didn’t say a world in the cab ride home.

Once you’re back at home, reality starts to crash into you. I hugged my wife and we had to tell our children. One started crying, the youngest one plainly asked me if this could kill me. After reassuring them, I had to pick up the phone and let some people know about what had just happened.

The toughest call I ever made was the one to my mom, who’s a cancer survivor herself. She was shocked and I’m sure she held in her tears just till the phone call was over. I quickly decided that I would put out a message on my Facebook as well. I wanted to be able to talk freely about what was happening to me, so I just threw it out there.

Even though I was emotionally exhausted, sleep didn’t come easy.

The following week was just a haze. I was totally unable to focus on anything really, I was tired all the time, and felt like crying. I was fortunate to have my wife, my psychiatrist (I am on the autism spectrum), and my two home nurses that usually take care of my medication. All of them are very supportive.

I had a CT scan of my chest on Wednesday and a scan of my abdomen on Thursday (for which you have to drink some strange liquid). The nurses can not give you any results so you are just left in the dark, clueless of the state your body is in. On Friday, I had to go for a COVID test at my GP’s office, but that turned out okay.

The other upside was that my doctor already had results of my ct scans and bloodwork – the first good news in days. He told me there were no metastases found and that my lymph nodes were clear. Also my tumor markers were at a normal level. This doesn’t mean however you don’t have cancer. Just not every type of TC increases your tumor markers. It could however suggest that I caught it early, which for every cancer is a good thing. I guess this was the first night I finally was able to sleep a bit better. One worry less.

On Tuesday the 22nd the big day was finally there. I’ve had multiple surgeries before, so I kinda know the drill. But for this one, I was extremely anxious, after all I was going to lose one of my balls. But the hardest part was facing this all on my own, without my wife to support me. COVID-19 makes dealing with cancer so much harder.

So anyway, there we go.

Check in at the hospital about three hours in advance. Get appointed to your room. One of the nurses comes to ask about your medication, another to take your vitals. Suddenly a nurse comes in, saying, “Hello we are here to shave you!” Once again, everything in the open, this time for two nurses. By now I was getting used to having someone else than myself or my wife touching my parts.

After some waiting they come and roll you in your bed to the operations quarter. Then prepare your IV and ask some final questions about allergies (and they'll also ask you your name and birthday for a gazillion times and the procedure you're in for). You'll probably also see your surgeon just before the grand event. Once in the operating room, everything moves quickly. They put on some buttons, give you an oxygen mask and before you're well aware of what is happening, you're knocked out by the anaesthesia. All in all this seems more scary than it actually is. It is basically like falling asleep, nothing really exciting. The surgery takes about an hour or so.

After the procedure, you wake up at the recovery room.

I was in tremendous pain at that time, the doctor told me it was a minor surgery, so I wasn't prepared for this. Usually you stay about as long in recovery as the operation took, but one of the points of being in recovery is pain management, so they kept me there about half an hour longer. When you're well awake and your pain is managed, they will bring you back to your room.

After some time you'll get something small and light to eat. A nurse will come by several times to see how you are doing, check your vitals again, and perhaps change your dressings.

I chose to spend the night at the hospital because that made me feel more at ease.

The first time going to the bathroom was rather uncomfortable I have to admit, but I could walk alone. That night in the hospital was quite painful, but if you are in the hospital you can ask for the necessary pain medication.

I also called the night nurse, because in the middle of the night I had an experience which made me freak out! My entire sack had all of a sudden turned completely black. I thought I had an internal bleeding or something, it was quite the panic. But when the nurse came, she assured me it was all completely normal. Just major bruising as a result of the surgery. Yet another surprise I wasn't expecting.

After breakfast the next morning, a nurse came to help me wash up, which I have to admit was an excruciating experience to me. They changed the dressing on my incision and after the doctor came to check up on me I was discharged. Glad to be back at home, but still rather tired and sore.

Then comes the everlasting waiting game, which seems to be an inseparable part of having cancer. For the doctors to know your exact staging of cancer and your subtype of TC they need the results of a pathological examination. This is not an easy accomplished thing. It might easily take two or sometimes three weeks to get the results back to your urologist.

Courtesy of Justin Birckbichler

Those weeks are some of the strangest I have experienced in my life.

You’re going to be anxious all the time. I also didn’t feel well enough for any physical activity and mentally to shake up for anything remotely requiring concentration. Netflix and other streaming services were my best friends in such times.

After two weeks of walking up the walls, I finally had my appointment to get my results and check up by my urologist. I was even more nervous than the first time, but I did ask permission for my wife to accompany me this time, which was exceptionally allowed. The first thing the doctor did was checking my incision, which was alright. But then came the important part—the pathology report. Turned out removing the testicle was indeed necessary. I had a 100% seminoma, which is a malignant tumor, so truly cancerous.

But fortunately for me seminoma is the less aggressive kind. It often happens that they don’t elevate tumor markers so that fit as well. Since I had no metastasis on the CT scans and the tumor was only located in the testicle itself, I was considered to be stage 1.

Stage 1 means that, for now, I do not need chemotherapy or radiation. However, remember how I said that cancer is a waiting game? Now I’m under “active surveillance.” This basically means that I’ll be followed up every 3 months with the complete work up of scans and bloodwork. And of course the inescapable physical exam of the remaining testicle and the lymph nodes in the groin. All in all you could say that this is a very good thing. If something would turn the bad direction, they will quickly be there to address the issue with the adapted necessary treatment.

On the other hand, this does make it mentally taxing.

I like to call it scanxiety. You never know what you’re gonna get. It’s like getting a three months free pass to life, but then comes another reality check. Will it be good or bad news? The same stress all over again. For me, those are not comforting thoughts. So I try to find distractions, get back to my hobbies and my regular day-life. Honestly, I’m still struggling with this. I’ll wake up in the middle of the night with night terrors of everything that could possibly go wrong. I know it’s futile, but somehow my subconscious is stronger. I’m now almost five months post-surgery, but I need more time to give it all a place in my life, to adjust to my changed body. I still experience nerve pains on a daily basis, some days worse than others, as if the removed testicle is hurting.

There are many things that keep me worried and scared. But writing down my story has been helpful to me in my own way, and I guess I’ll keep on doing it. I hope this story can also help some others. Of course this is just my cancer story, I know I’m one of the lucky ones. But having cancer taxes us all mentally, there is no escaping that.

Awareness of testicular cancer is virtually non-existent.

My GP and Urologist were amazed at the fact that I did a self exam. I would like to improve awareness in Belgium. However, as we only get around 300 cases in the country a year nobody, not even any cancer organisation, seems to give a damn. I use Facebook a lot and share monthly reminders to self exam every month.

Not a single male person that passes by in my life goes by without the question when did you last checked your nuts. I always joke that they could turn it into an interesting way of foreplay and have their significant other do the check for them. I’m getting some brochures to spread at my hospital and urologist office.

I’m recovering from hip surgery and doing a lot of physiotherapy. I recently got a new physiotherapist who gives me exercises to do. I already gave him an exercise for himself: a regular testicular self exam.

Be sure to connect with David by visiting him on FB as David De Wilde and on Twitter as @DavidDeWilde4. Until next time, Carpe Scrotiem!

Know someone (or even yourself!) who is supporting TC awareness and would be willing to share their story? Drop their name, contact, and why they should be featured into this Google Form and I’ll reach out to them and/or you!

This post originally appeared on A Ballsy Sense of Tumor on March 11, 2021. It is republished with permission.
