

# Dealing with Insulinoma

## **It's confirmed as an insulinoma.**

Those words were both terrifying and strangely reassuring. Terrifying in that I knew I had a rare tumor that can be fatal if left untreated, but reassuring in knowing the symptoms I'd been suffering where real, had a name and could be treated.

Insulinoma is a functional tumor in the pancreas that creates its own insulin in addition to that already created by the pancreas. They are slow growing, often no bigger than 1-3 centimetres and in 95% of cases are benign. There's no real reason why they occur and little is known about them. To say they are rare is an understatement. On diagnosis the doctors confirmed the chance of having an Insulinoma was 0.4/1,000,000. I joked that my mum had always said I was one in a million.

## **Something's not right.**

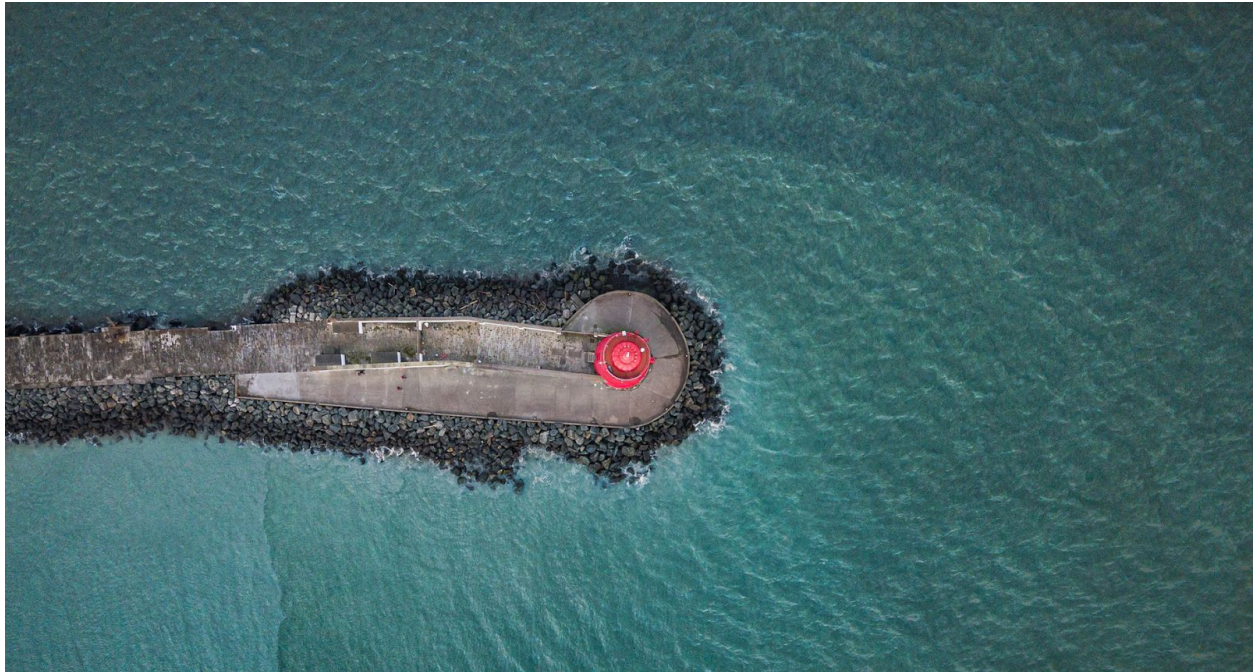
It all started back in January 2019 when living in France I returned from a mornings ski touring semi confused and lacking coordination. Little did I know but I was suffering a hypoglycemic attack as having not eaten, and just climbed a mountain peak, the tumor was pumping out insulin. The blood sugar crash led me to slurring my words, struggling to maintain balance both of which disappeared once I ate breakfast. This happened a few times and I grew more suspicious.

A few months later the problems increased. On a trip to the gym it ended with an unfortunate fellow having to help me out of the shower when another attack left me unable to control my limbs. A moment he may struggle to forget.

Another attack saw my boyfriend finding me at home having trashed the kitchen trying to make lunch. Again I was slurring my words, feeling disoriented and talking randomly about visiting IKEA. As before, once I ate I returned to normal. Thankfully on this occasion my partner made a video which would prove invaluable when visiting the GP.

The GP visit was the gateway to treatment. When I first described the symptoms the doctor sympathised and explained how he often got dizzy after rowing and exercise. My shoulders sank as I realized I would have a fight on my hands to prove I wasn't psychosomatic. My boyfriend retrieved the video which instantly changed the doctors view. The GP showed seriousness and he immediately deleted the notes he'd started to write. He recommended I see a specialist to do further tests. I felt relief and overwhelming gratitude that my boyfriend had the foresight to video one of my attacks. I left thinking I'd cleared another hurdle.

## **The kindness of strangers**



South Wall Walk, Dublin

Then came a business trip to Dublin where the seriousness of what I had become undeniable. I woke one morning, the sun shining over the bay and decided to walk along the south wall out to the lighthouse. Having reached the end of the wall I realized I wasn't feeling great and didn't have enough food with me to stave off an attack.

As I retraced my steps back to the streets of Sandymount, I started to experience an attack. Within minutes I was losing balance and heading confused towards the sea. At one point I grabbed a clump of grass thinking it might contain something that would restore order. A stranger came to my aid. Him and his wife out walking the dog saw my lack of balance and coordination. They immediately asked if I was okay. Wonderfully they asked whether it was something to do with my blood sugar. I collapsed into a nearby bracken and the man ran to get me sugar as his wife and dog looked on bewildered but offering kind words of reassurance.

On eating three Cadbury bars (the only good thing about having insulinoma), I immediately came back to reality. I thanked the pair and was greeted by another kind stranger who offered to walk me home. During the walk he told me he'd recently been diagnosed with diabetes. I told him I wasn't diabetic but that doctors were looking into it.

### **Dr Google will see you now**

On returning to my Airbnb, I stupidly researched hypoglycemia on the internet. What I found started a spiral of fear that I struggled to get out of. On page 1 of Google search results I found Insulinoma and on page 28 the same. No other conditions, just Insulinoma. I frantically

searched using other terms but everything suggested that hypoglycemia wasn't an illness but ominously pointed to a more serious condition. I felt finding out I was diabetic would be easier. Some searches caused greater confusion as some sites used the same content for both Insulinoma and Pancreatic Cancer.

Like a Wikipedia search I was soon reading about Insulinoma and within an hour I knew enough to be dangerous. I'd downloaded patient case studies, trans European medical studies and came to the conclusion that what I was facing was dangerous, serious and not something I believed I had the strength to deal with.

In tears I called home and immediately set out to return to London. Arriving at home I was distraught. My boyfriend opened the front door to find me quivering in tears. I told him what my research had found and explained that if it was malignant it might be bleak.

My boyfriend looked on in disbelief as I imagined myself into an early grave. Being a pragmatist he hugged me, told me we'd deal with what came, but confirmed that the consultant had mentioned it could be a tumor. That explanation floored me. I rummaged through my mind replaying the visit to the consultant in my head. Tumor? When did he mention that? Of course I'd missed it as my mind was elsewhere focusing on work, meetings and memos. This is when I realised the benefit of having someone accompany you on your visits to the consultant. They often pick up things you discount or simply don't want to hear.

### **Let's do an MRI scan**

Over the next two weeks I suffered a complete mental breakdown, part of which was on a long planned holiday to Gran Canaria. The only saving grace being that you can cry your heart out behind summer shades and no one's the wiser. I finally got confirmation of the MRI appointment. The consultant, seeing my obvious distress and inability to cope, had bent the rules to order an MRI out of sequence from the other tests.

The MRI itself was a strange experience. I lay there nervous but also relaxed. The headphones they provided did their best to distract but listening to the traffic update and of junction closures on the M6 only added to the bleakness. As I lay there, my mind began to wander. I thought about my boyfriend, friends and family and questioned what I would do if the news were bad. Thankfully the radiologist pulled me out of the tube before I had time to consider memorial music.

Waiting for the results was the worst. Every day felt like a month. The medical profession seemed oblivious to the mental pain waiting causes. Finally they confirmed something had been seen in my pancreas and potentially something on my liver. Again relief mixed with fear and terror.

## **Facebook to the rescue.**

A few days later I stumbled across a Facebook group and it changed everything.

Run by a remarkable woman called Enola it offered those diagnosed with Insulinoma or their loved ones a place to ask questions, talk and support each other. I shared regular updates with the group and supported others in the same position whether through comments or just a simple emoji. It was great to be able to speak to people who'd gone through the same treatment I was looking at undertaking.

The next few weeks went by in slow motion. Trips back to the consultant where I demanded all sorts of tests. I informed the consultant what Dr Google had indicated. He explained it was unlikely and rare but not impossible. I asked for an MRI to find the tumor to which I was told other tests were needed first. I started a cycle of over 20 blood and urine tests. I also completed a Glucose Tolerance Test. All of this while everyday connecting with my new Facebook pals to keep them updated and support others.

## **It's 1997 again...**

The consultant decided to conduct a 72 hour fast whereby I'd been deliberately starved with the expectation that an Insulinoma would prove its presence through the inducing of a hypoglycemic attack. This is part of the gold standard for diagnosing Insulinoma. After 18 hours since my last meal I immediately began searching for imaginary coins on the floor of my hospital room. The nurses asked me what year it was to which I exclaimed it was obviously 1997. In my head Tony Blair was prime minister and Brexit didn't even exist.

Afterwards I laughed that I'd have liked to have stayed in 1997. After giving me 10% glucose intravenously, I returned to normal and back to 2019, albeit with a pounding headache and zero appetite.

More tests followed. Nuclear medicine as part of a PET-CT was next used to localise the tumor. It didn't find anything - which is actually quite common. Again I cried in front of the consultant only for him to offer some realist advice that at least the scan hadn't lit up like a Christmas tree. That's true I said, that's true!

Soon there was talk of visiting a specialist nuclear medicine facility in Switzerland where they had a new test that only sought out Insulinoma tumors.

In the end the consultant decided that an endoscopy was the next best step. The idea of a camera going inside me filled me with awe more than anything else. The camera experience itself was horrendous with the camera attached to what can only be described as a garden

hose. Thankfully the sedation and my desire to deal with the pancreatic intruder got me through it. I spent the session telling myself I was at a high end spa.

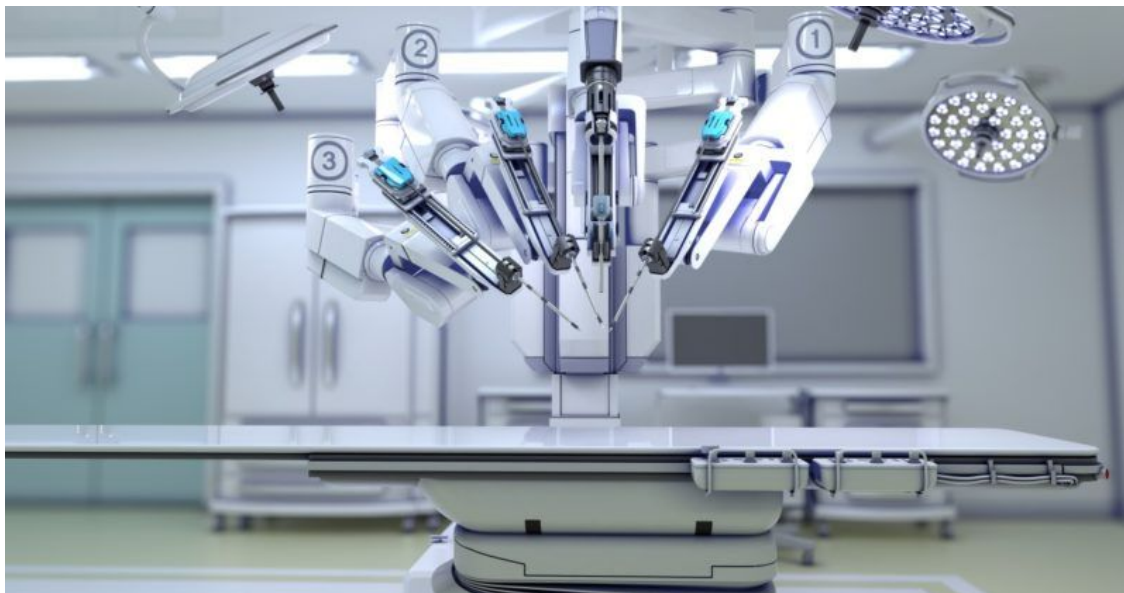
The quality of the photographs they took was instagramable and this time they found it. Looking like a recent blister. Just sitting there in all its pink glory.

So now we knew what it was, where it was and the only thing left was to operate. I immediately asked how quickly it could be removed and what the operation and recovery would be like. The endocrinologist informed me he'd spend some time researching the best surgeon for the job. He read my mind when he said 'I don't want any Tom, Dick or Harry operating on your pancreas' - quite.

### **Robotic Surgery**

A few weeks later, by which point I had become a world expert on Insulinoma, I met my surgeon. He walked in looking confident and immediately began to describe what he was planning to do.

He told me that robotic surgery was the best option and that he would use the Da Vinci robot to conduct the procedure. He confirmed the robot would allow for more accurate removal and speedier recovery. I asked when he could operate and he opened his filofax (strangely old school and comforting). How about Monday? I recoiled in terror and immediately thought I'm not ready to undergo major surgery in five days time. He then suggested we wait until he was back from holiday and we settled on 12th November.



The Da Vinci Robot

The 12th November arrived like a sudden but forecast storm. I'd reached and watched some YouTube videos featuring the robot. It was difficult to tell the difference between Da Vinci promotional videos and HG Wells, War of the Worlds.



D-Day - Outside The Cromwell Hospital, London

I arrived at the hospital knowing that I was facing the biggest challenge of my life. I also knew that a fellow sufferer was facing surgery on the same day at UCH London. I thought about us both and hoped for the best. On meeting the surgeon he inspired confidence and I gave up worrying and decided 'Que sera, sera'.



Intensive experience in intensive care

Waking up in intensive care was a surreal experience.

A mix of pampering and total awe that I wasn't in major pain and was able to talk to my family. My boyfriend and parents had visited a nearby pub sinking a few merlots as they waited for news. I lay motionless scared that moving might mean my pancreas falling out or staples ripping open. Constant injections kept me awake as they pumped in drugs to prevent future growths. I had a wonderful nurse called Albert who demonstrated the true vocation of healthcare. He worked tirelessly to keep me comfortable while answering my inane questions about his family life.

The next few days saw me learning how to walk again, having my first shower and coming to terms with changing dressings and carrying around a bag of gunk from a drain. I can honestly say I have more resilience than I thought.

On leaving for home my boyfriend dodged multiple potholes so as to avoid pain in my abdomen. Arriving at my front door I broke down into tears. I first checked out my bonsai tree having bought it soon after diagnosis on learning they live for 900 years. There was something calming about buying something so delicate that would outlive me 8 times over.



Bonaparte my beloved Bonsai - 46 years old

## **The road to recovery**

Over the next few weeks I gorged on Netflix (hallmark rom coms are my guilty pleasure), attempted a jigsaw, read 10 books, walked every day, each time a little further and started back learning French. A visit to the consultant in December saw them confirm my biopsy results (Grade 1-2) and future treatment plan. The 7 incisions made by the robot had healed well and 1 had totally disappeared. The consultant confirmed they will now scan me every 6 months for 5 years to keep an eye on me. I walked out into a busy London street realising how far I'd come.

## **So now that I've recovered from surgery and back running regular 10ks what have I learnt?**

Well I learned that love, family, friends and fun are all that really matters.

The biggest lesson is how I'd made a mistake in letting work take over my life. I'd spent 6 years working 7 days a week and sometimes up to 17 hours a day. I'd managed programmes and projects with up to 4 clients simultaneously often moving from one client meeting to another without even catching a breath. I'd spent so much time working that I'd forgotten the more important things in life. I'd neglected my boyfriend, family and friends for the sake of growing a



business, managing clients and winning praise. The sudden arrival of a major illness stopped me in my tracks and made me question life and what is important to me.

2020 will be the year I return to skiing, enjoy two weddings, visit my 94 year grandmother in Ireland, celebrate a holiday in gran Canaria with friends, visit St Petersburg, walk over the chain bridge in Budapest, discover the modernist architecture of Le Havre, finish my reading list, improve my French, reconnect with the Welsh language, embrace Yoga and Chinese medicine and of course return to work.



My granny is going strong at 94 years old. With my mum

A big thank you goes to all the wonderful strangers, friends and experts who helped me along the way. Above all to my endocrinologist Professor John Wass and surgeon Professor Long Jiao and my partner Dave and my parents. Thanks also goes to the radiologists, nurses and anesthetists who put up with my questions, scenario planning and tears. A thank you to my employer who gave me space to recover. I also can't forget those strangers who selflessly came to my aid when attacks struck.

Insulinoma is a very rare illness that many don't even know they have. Some are misdiagnosed with epilepsy or become obese eating to stave off attacks. If you know someone suffering the symptoms I mentioned encourage them to get checked out. As I told my doctor and consultant, each person knows their own body.

Like any illness you need to learn to move on. Writing this up hasn't been easy and every now and then flashbacks take me back to the consultants room or intensive care. I often sit motionless and overwhelmed until something distracts me. No doubt it will lessen with time. The one thing I do know is that life is for living and it can be upturned at a moment's notice.

Insulinoma may have been a blessing in disguise; it's one I won't waste.

### **So my top tips**

1. **Educate yourself on the illness** so you can have more informed conversations with your consultants.
2. **Join the facebook group** to ask questions, get support and help others. Remember the group is full of fellow sufferers and their families. They can't diagnose or give medical advice on results or scans.
3. **Don't worry if your scan doesn't find the Insulinoma** - this is quite common. They will conduct others tests to help locate it.
4. **Record your blood glucose** at home and collect evidence of your condition for the doctors and consultants.
5. **If you can, take another person with you to your appointments.** They will pick up on things you might have missed - and take notes of what the experts are telling you.
6. **Ask questions at every step** and don't be afraid to question your treatment plan.
7. **Once in recovery take it easy and listen to your body.** Don't expect to be doing housework or 10K runs. Enjoy the time out and let your body heal itself.
8. **Keep positive** as having that outlook will speed up your recovery.