

No more blues for Adam

sarcoma



At the age of 15 he was diagnosed with a rare form of bone cancer and lost half his leg. Seven years on, Adam Gill is cancer-free, is a BSc in molecular and cellular biology and has just gained a Masters in research. It's a good news story for World Cancer Day, yet Adam has been left with a condition that has affected every aspect of his life: epilepsy. 'If I had to pick between just having the cancer, and just having the epilepsy, I'd pick the cancer without hesitation,' he has said.

Shaun Shackleton reports



Aged 17 and nearing the end of his treatment for Ewing's sarcoma. (Picture by Peter Frankland, 12850740)



Adam Gill, back home in Guernsey after attaining a master's degree in research. (Picture by Adrian Miller, 12893412)

Adam with mum Ariffa Gill. (Picture by Adrian Miller, 12893407)

WHEN I interviewed Adam Gill in March 2008 he was 17. Two years earlier he had been diagnosed with Ewing's sarcoma, a rare form of bone cancer, and had just returned from Southampton General Hospital and his penultimate chemotherapy session. He'd already had 13 four-day sessions and, at the Royal National Orthopaedic Hospital in Stanmore, had had half his femur removed and replaced with titanium. On top of that there had been regular physiotherapy, numerous blood/platelet transfusions and countless blood tests and injections.

'It was a hell of an excuse to get out of sitting my GCSEs,' he'd said, with typical irreverence. Since then he's been through A Levels ('A+ biology, A in physics and chemistry and B in maths, but we don't talk about that. You do them, get results and no one ever asks you about them again') and the University of Bath, where in 2014 he

became a Bachelor of Science in Molecular and Cellular Biology. In December last year he graduated with a Masters in research. 'I'm now one of those slightly uncomfortable students that has plenty of free time,' he admits. But surely he deserves the rest? 'It's tough, as in looking for things to do next. The Masters was the hardest thing I've ever done, but the most worthwhile. It was very intense. It's another letter, I guess. It means even less now than when I started. CV-wise, people are asking for PhDs. Regardless of that, it made me grow a lot as a person, which I'm proud of.'

Seven years on, there is both good and bad news. In cancer terms, it's the former. 'You have to wait five years – it's a very statistical thing. But after that the risk of [the cancer] recurring is much less, so there was always the counting down... until then it's five years later, and it's "p*** off, we don't want to see you".' The bad news is that a latent form of epilepsy, which the chemo

unmasked, remains. 'I didn't see that coming... it became devastating. Right now, today, I got a call from the pharmacy. I've got four different anti-epileptic drugs – I can't remember how many I've tried. Some made it worse, some no effect, some made me throw up. It's a bit of a rollercoaster. You don't really see it coming; it's unpredictable. 'Sometimes cancer was easier to deal with than the epilepsy – it's hard treatment, but I could deal with that. But epilepsy affects you every day. I can't just nip out because I can't drive. It's hard, I can't overstate how hard. [But] I can't compare the two and wouldn't put them side by side, because both are worthy of recognition.' Other side effects include forgetfulness. 'I need extra time to do things... no one knows why it happens.' There may be hope, however, in the form of a new treatment. 'I talked to my specialist about it – we get on well. There is one device which stimulates the nerves, like a pacemaker, and pulses every few minutes. They've been tested on

'Some cancer easier with the epilepsy, hard treatment but I cope with the epilepsy you ever

Adam



Adam with his drum kit in 2008. (Picture by Peter Frankland, 12850763)



In 2010 after winning an award for 'triumphing over adversity' as part of the Guernsey Young People's Awards. (Picture by Adrian Miller, 12850754)

Dispatches from the cancer ward

HERE are a few examples of Adam's blog which he wrote during his treatment for Ewing's sarcoma and which shows his sharp but dark humour. Some of the language used is, understandably, strong.

Previously, things like genitalia and going to the toilet were unspeakable, confined to the shady corner of euphemisms and smirking eight-year-olds. Now, to me, they're just items from the human anatomy and necessary bodily functions.'

Anyway, using my natural charm and general awesomeness, I convinced two of the nurses on duty to possess a certain amount of awesomeness themselves, a fair amount of musical talent, a guitar and a recorder to serenade me at 8 o'clock in the morning with a (well rehearsed I'm sure) song to awaken me from my gentle slumber. I was the envy of the entire ward, though perhaps not everyone's favourite patient – when the two nurses in question play their instruments, they play them so everyone can hear. Although unconventional, it was certainly a very welcome change from being awoken by a beeping drip machine, a nurse changing my chemo drugs or a screaming child.'

Despite having a cool leg brace thing fitted and subsequently hobbling, I'm not Batman. I'm also not Bane, despite being able to do a half decent impression of Tom Hardy's voice and definitely having taken my fair share of medication. 'No, my next slew of pictures simply chronicles me, learning to walk again. I guess it was easier the second time round, but it wasn't something I was expecting to have to do twice.'

But, as the French say, "c'est la vie". It's easy to get p***** off with physios and curse consultants, but at the end of the day it's just a waste of time and, more importantly, energy. Besides, it's no one's fault that it has to be this way, it just is. It sucks. It's unfair, but life's unfair.'

You shouldn't underestimate epilepsy. If I had to pick between just having the cancer, and just having the epilepsy, I'd pick the cancer without hesitation. Cancer can ruin my leg. Epilepsy has eked its way into every nook and cranny of my life, and decided to p*** on it continuously. But I beat it once. I can beat it again.'

Having seizures isn't the biggest problem though. I mean, I've spent rather too many nights in A&E because of them, and had rather too many stitches, but that's not the end of the world. It's the constant fog of five drugs jostling for space in my head, the lack of memory of what happened a few hours ago (let alone a few lectures ago), and my overall lack of knowledge of what my own brain will decide to do to me next. 'I am a disabled person. Sometimes I'm thankful: I get to live on campus at uni, and I have a convenient excuse for getting out of a lot of unpleasant things. But I'd trade all of it, even my free bus pass, to be able.'

Hospital humour

IN 2008 the Guernsey Round Table's Richard Grindell presented Adam with a Nikon D60 digital camera as part of the charity's Children's Wish programme. He still has it. 'It's a bit battered and bruised but I use it. The family always say, "Come on Adam, take a picture" and at uni I'd get involved taking [them]. It's always good fun. I've learnt a lot about photography.' But along with science, Adam's great love is music. This was evident when I first read his blog eight years ago, on which he'd written Ewing's Sarcoma Blues, an unflinching, sardonic and darkly funny song about his condition. A few verses:

I've got Ewing's sarcoma
In my right hip,
And chemotherapy
Well it feels like **** .
It's Ewing's sarcoma.

Ewing's sarcoma
gets you down,
But I've got no eyebrows
So you can't see me frown.
It's Ewing's sarcoma.

Alopecia,
Your hair falls out,
I'm definitely better
With hair than without,
It's Ewing's sarcoma.

Adam still has a drum kit set up at his parents' house and he's still learning to play the guitar. 'The guitar I think is something you pick up yourself,' he said, then added, laughing, 'though if there are too many chords in a song I don't bother to learn it.' Now he's in Guernsey there's one thing he misses about university. 'I was on the music committee... we had a music room with a set of drums and we could all go there and jam. It was ideal.' That is something he would like to see happen in Guernsey. 'It's a small place but there's lots of talent here. I'd like to try and find a way for musicians to meet up and play together.'



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dogs and there have been some trials on people. I'm down for a trial but the epilepsy I have is relatively rare. With the trials there is funding for common epilepsy, but for uncommon, you have to wait. Cancer, treatment, epilepsy, medication, studying, exams, success. After all this, the question many ask him is, what's next? Adam said that the question throws him off guard. 'I don't know what's next.' He wants to carry on being an academic scientist but has some forthright opinions about the academic world. 'The more time you spend in academia, the uglier you see it is,' he said with brutal honesty. 'It's hard to put it diplomatically. It's a systemic thing. For example, get a PhD and in the UK there's an estimated 23% chance of going on to do post-doc research. Of that 23% between three and eight per cent get to be a lab head. But you're not told this at the time. You're wanting to cure diseases, unravel the mysteries of nature. The higher up you climb, the pyramid is getting narrower and

people are dropping off. 'In terms of academia and research I ask myself, "Is there any point in going down that route?" I'm in a privileged position, I'm a white man. If I was in my sister's position I'd find it harder. Women have a lot harder time. 'I have to emphasise that I don't want to dissuade anyone wishing to go into it, I'm the most pro-science person you'll meet, but people should be aware. I had no idea. It's just meeting people who have become, scarily, disillusioned.'

When I first met Adam he was making quite a name for himself with his blog – or, as he described people describing it, 'that kid with cancer and the blog'. Called gillspatch, it had the subtitle 'randomness, awesomeness and Ewing's sarcoma' and was an online diary in which he talked, in no-nonsense, often expletive-rich dialogue, about his life with cancer. There are no recent posts. 'I don't think I'm interesting any more, now that I don't have a life-threatening condition,' he said,

dryly. 'I look back on it every now and then. A teenager with cancer was unusual. It was a bit more difficult to set up a blog in those days. But I'll keep the blog up there, as a time capsule. 'It's funny you should mention the blog and writing. It's maybe something I want to look at, the communication of science might be a lot less difficult to get into.' It was good meeting Adam again. Talking to someone who has such a positive and honest attitude to life always means more than just a story. It's obvious that he is still up against it, but he is tackling his epilepsy with a strong determination to beat it and a dark but sharp sense of humour. When I told him it was good to see him he said: 'Is that because last time you didn't think you would again?' Returning his honesty, I replied: 'Well, yes.' As I was about to leave he reiterated the old 'what's next?' question. 'You go to uni and you come back after five years and it's life experience. What's next is... I dunno. The unknown.'