

Working with cancer

I was diagnosed with terminal cancer in October 2017. I've always been a bit of a fitness freak, and during the spring and summer 2017 I was training for a couple of sprint triathlons I was planning to do in early autumn. Sometime in February I came home from a run and my leg started to ache. I laid off the running for a week and tried again. Same result. The leg would ache for a few days and then appear to be ready for action. It soon proved it wasn't.

My first thought was that it was an old football injury. It was hard to tell if the pain was in the knee or the tibia. I went to see a physiotherapist who was puzzled but ruled out the knee. It was time for a visit to the doctor's. She was just as bemused and referred me for an X-ray. She showed it to me when it came back. There was some shading down the right tibia which, she said, 'needed investigating'. She wasn't wrong.

In the next few weeks I had several scans, an alphabet soup of MRI, CT, PET etc. Finally came the meeting with the consultant. He didn't quite put on a black hat, but he did have a serious-looking nurse with him. It wasn't good news. Melvyn the Melanoma had returned, and, typical of the sneaky little devil, had returned where I least expected him. He'd done that last time as well. His latest incarnation was as a bone cancer, and for good measure he'd sprinkled some fairy dust into my liver as well. Basically, I think he'd got fed up with messing around.

He first appeared in 1998, in his classic incarnation, as an itchy spot on the back, helpfully just as we were moving house. By a fluke, and thanks to a cancellation, he was diagnosed and removed on the same morning. 'Well', I thought, 'that's good, that's the end of that'. I had to declare it to the insurance company who were covering my uncompleted mortgage. Their cheery response was that my monthly premium would not be £15, as arranged, but £90. I protested loudly, but of course the more I looked into it the more I realised that Melvyn was a seriously risky chap. He might be gone, but he might also have left mini-mayhem morsels lurking about inside me. Hence the new premium.

All was well until 2007, when I'd just passed my 58th birthday. Suddenly a lump appeared in my right armpit. I recall the exact words of the very experienced consultant: 'it shouldn't be related to the previous melanoma after all this time, but I'm going to lay money that it is'. He treated it accordingly. I was in hospital within a few days having the contents of my right armpit scooped out. Exit Melvin, stage right, accompanied by lymph nodes. He was in a sulk, of course, so unbeknown to everyone, and just like last time, he left a few bits to bide their time: have cancer, will travel. The surgeon thought he had got him all but admitted that he was slippery as an eel, so you could never be 100% certain.

I was monitored every three months, then every six months, for five years. By this time, I'd taken retirement a year early from the schools' inspectorate and was having the life of Riley in my own special measures. Of course, Melvyn wasn't dumb enough to reveal himself when being checked. It wasn't until ten years later, when he was almost forgotten, that he made his decisive strike. Being what my grandmother used to call 'artful as a cartload of monkeys' he decided to settle in the leg while all the attention was still on the armpit. Somewhere in his age-old genes lies the talent of a military strategist. No point in engaging

the enemy head-on, just creep round the back while their attention is elsewhere. If you pass some interesting sites on your way to the destination just drop a grain or two of collateral damage there as well. My liver obviously came into that category.

So, there I was suddenly in the terminal when I didn't even know I'd booked a flight. My best hope was that the flight would be much delayed, an experience for which flying with Ryanair had fortunately prepared me. However, hoping that the flight would be further delayed was a new experience. Now I was lucky enough to be referred to someone who is probably the best oncologist in the world. Gill is more like a friend than a doctor and shares my sense of humour. Or probably pretends she does! She devised a strategy for me involving two targeted immunotherapy tablets, dabrafenib and trametinib. I immediately baptised them Dab and Tram.

They set to work straight away, and the first indications were just what we needed: my relationship with Melvyn was cooling and his hot spots were shrinking. The CT/PET scans indicated that he was but a shadow of his former self. Unfortunately, it didn't take him long to find a solution to that. My liver, which had always been very well behaved, suddenly started to mess around in a way only he could have encouraged. I had sweats, nausea and a delight new to me called rigors, where you shake like a jelly for twenty minutes, pausing briefly to be sick and then shaking for another twenty minutes, before being sick again. It certainly passes the time! My wife and I were backwards and forwards to the hospital like yoyos. Treatments and blood tests became routine. Finally, one day Gill, who had been trying to get my blood pressure up and my temperature down, said, memorably: 'I'm afraid you're going to have to spend the night with me!'

I was whisked off to the cancer ward for further observation and treatment. In the liver there is an ingredient called bilirubin. No prizes for guessing that, as Billy Rubin, he became a lead character in the drama. He has the unique gift of making you turn yellow, which fortunately, as a Norwich City supporter, was my favourite colour. On blood test readings his scale is meant to be between zero and twenty. My reading was 257. Billy's approach was obviously less subtle than Melvyn's. Someone had been winding him up and Dab and Tram were the obvious suspects. They got so drunk on their success at shooting all the hot spots that they started to fire indiscriminately everywhere else as well. My liver was a sitting duck. Quite rightly, they were fired, and trooped off miserably: hero to zero in three months.

Meanwhile, just before Christmas, Gill had referred me to Ben, a bone surgeon, to investigate the leg. He studied the pictures, the hot spots here clearly not as welcome as on a weather map. He gave me a few options. The one I chose was the one he described as 'opening up the leg, scraping the crap out of the bone, filling it with cement and sewing it up again'. A concrete solution. The other alternatives seemed a bit feeble by comparison, and I like a challenge. My main concern was that, with a leg full of cement, I would sink straight to the bottom of the swimming pool, closing off that avenue of pleasure. I thought back to my football career, and how useful the leg would have been in breaking the toes of aggressive opponents. Ben worked a miracle to get me in for surgery just before Christmas, and I spent the festive period as trussed up as the turkey. The wound was much admired by my grandchildren when the dressing came off. A freshly-sewn grandad was quite an attraction.

The first four months of 2018 were spent diagnosing and then dealing with the liver problem. A number of possible causes were ruled out and I was given Rifadin, a foul-tasting medicine to be taken initially once and then twice a day. Riff O'Din, the Irish liver specialist, took three months to find Billy Rubin and knock him down to size. He was on his own, as all the other treatments had to be stopped. Billy was an extremely annoying adversary. His main tricks were to make me itch like a dog and turn all my food into cardboard. Gill prescribed some ointment for the itching, but I could tell that she knew it probably wouldn't work. It didn't.

However, her recipe for the food did work. 'Try stuff that you had as a child', she said. She'd obviously researched the 1950s: 'try rice pudding, try banana custard, try Heinz tomato soup'. So we did, and they became the only non-cardboard items in my diet. Repetitive, boring, but strangely comforting. Not unlike the 1950s, in my recollection. I remembered going to the shop for my mum. 'Half a pound of cheese, please'. 'Red or white?' No need to linger in the cheese aisle, trying to decide between Wensleydale, Camembert or Dolcelatte. Life seemed uncomplicated, until you got ill and, in the absence of penicillin, had to spend a week in bed. Even my rose-tinted spectacles couldn't remove the hot poultices, the cod liver oil and malt (think Swarfega), or all the other grit in the Vaseline of life.

Finally, in late April, Billy Rubin was reduced to 17, so it was game on for further treatment. I was to meet a new friend, Liz, easier to remember than her longer name of Pembrolizimab. Liz is administered via a three-weekly infusion. Being a sensible female, she is much subtler than gun-toting Dab and Tram. Rather than try to blast Melvyn out of existence, Wyatt Earp style, she encourages my immune system to do the work itself. After all, it took its eye off the ball rather badly when Melvyn turned up, so it was definitely time for it to earn its keep. No room for passengers on this bus!

Of course, following its earlier lapses it had rather lost confidence, so that's where Liz comes in, encouraging and supporting it. She uses the Obama slogan 'yes, we can', which completely trumps the mendacious alternative 'make Harmer great again!' At the time of writing, six treatments in, Melvyn has grown only very slowly, despite the gap in cancer treatment, and Billy Rubin is back in his box. All is going so well that I felt I needed a sideshow to stave off the boredom. Lenny the Lymphodoema, come on down!

We have a wonderful facility at the Norfolk and Norwich hospital called 'The Big C Centre'. Staffed almost entirely by volunteers, it provides a number of opportunities for cancer patients and their relatives, one of which is free massages. It seemed a good club to be in, even though you might prefer not to be! I remembered the old Groucho Marx joke: 'I wouldn't be a member of any club that would have me as a member'. I had my first free massage, and Louise, the masseuse said: 'have you ever noticed that your right arm is bigger than your left?' As someone capable of walking obliviously into my house over a line of corpses, of course I hadn't noticed. 'I'd have that looked at', said Louise, so I mentioned it the next time I met Gill. 'Oh, that's a lymphodoema', she said.

So, the Boy from Lymphodoema went walking, not to Ipanema but to the clinic for some treatment and advice. I remembered I'd been told ten years before, with the enforced departure of Melvyn and the nodes, that I'd almost certainly have trouble with the arm. Gill

thought that the reason I hadn't was because I exercised so frequently, and religiously did all the arm exercises I was given. She surmised that the reason the problem had broken out now was because I'd been unable to exercise during the liver crisis. As I understand it, and with apologies to medical experts everywhere, it seems as if the lymph fluid circulates around its own system, just below the skin, removing rubbish and transferring it to the blood system for action. It's an internal waste disposal system. Since my 2007 operation, I've had an obvious road block in my right armpit, and the fluid has finally taken the opportunity to pool in the arm, in the same way as the waste piles up when the dustcart can't get through. Lenny took his chance: 'better late than never'.

At the lymph clinic, I was soon assessed. The right arm was 11% bigger than the left, and if that continued I would resemble a barrage balloon and be prone to lateral take off. I was prescribed an elastic sleeve to wear and given both a 'drainage routine' and a series of ten exercises to do every day. I do them night and morning, time consuming but not arduous. I could easily fall asleep doing the drainage, which involves cuddling your neck and chest while lying flat on the floor or in bed. Hoping that I'm not being observed, I remember my then eight-year-old daughter writing her 'news' in primary school. We went to the parents' evening and read that her daddy 'lies on the floor with my mummy's tights over his ankle, kicking two bags of sugar into the air'. I was trying to sort out a knee ligament injury, but I'm sure that nowadays I would have been referred to social services.

Following two months of exercise and drainage, I'm pleased to say that the difference between the arms has reduced to 4%. It seems as if I can't get rid of Lenny, but I can put up with him if he's not clinically obese. Of course, his seemingly svelte appearance is partly due to his elastic corset, but I suspect he's not alone in that. However, his Michelin man dimensions have been further reduced by the exercises, rather than the allegedly popular cosmetic surgery. I call them my pneumatic drill.

It's time to sum up, I think. Living with cancer is a very personal thing, and everyone has to find an approach that suits them. My strategies will certainly not suit everyone. In terms of attitude, I'm fortunate in that I enjoy exercise (it's a great advantage to be fit), I'm not a worrier (my poor wife has to worry for both of us), and I'm temperamentally somewhat fatalistic (Kay (aka Qué) Será, lovely girl, is a frequent visitor). Bringing those elements together helps me to keep smiling through the gritted teeth and to accept that it's no use crying over spilt milk. You just have to get on with it, and there is no point whatsoever in worrying about or lamenting your condition. It is what it is.

My second strategy is humour. Melvyn is a dictator who likes to have his own way. There has never been a dictator on the planet who could stand being laughed at. They're too full of their own importance. Think of Heath Robinson's wonderful cartoon called 'Practising the Goose Step', where a battalion of German soldiers is marching, all wired up to a marching goose at the front. You just know that Hitler, humourless little twerp, would have been infuriated. I don't know if Melvyn can be similarly wound up, and I may well die finding out, but I do know that exteriorising the problem, giving it a name and a personality and then poking fun at it is a good way, for me at least, of reducing its sinister impact.

The third dimension is philosophy. I first encountered it in 1968, when I spent six months as a pupil at a lycée in southern France. I was put in the philosophy section where we got an extra few hours of the subject each week. The course provided a panorama of philosophy through the ages, with summaries of what the great thinkers had said about topics as varied as memory, perception and above all the human condition. It was a life-changing experience, and a good preparation for trying to meet Kipling's twin impostors of triumph and disaster and, as he recommends, to treat them just the same. I found the rest of his famous poem 'If' less convincing: 'filling the unforgiving minute with 60 seconds worth of distance run' seems more of a recipe for a heart attack than a happy life. As a reminder that such recommendations are tough, I think of the wonderful French expression: 'with 'ifs' you could get Paris into a bottle'.

The Grim Reaper will win in the end. He always does, quite an achievement for a bloke armed with just a scythe. I do intend to give him a run for his money. A couple of years ago I visited the castle of Michel de Montaigne, the great 16th century French writer. He was also an early graffiti artist, or his servants were, as the walls and ceiling of his study are covered in quotes from philosophers through the ages. Because of his love of quotes, the footnotes in his books are always longer than the text. Among his own gems is one I find subtly brilliant and particularly relevant at the moment: 'to practise philosophy is to learn how to die'. I haven't fully learned yet, and I'm in no hurry, but I'm working on it!

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