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RTÉ's Tommie Gorman has spent 19 years going to Sweden to fight the type of cancer that killed Steve Jobs. This week, he took a huge gamble

- **For almost two decades the broadcaster has fought a battle with carcinoid cancer**
- **He has fought much of his battle in Sweden but will now put his faith back in Irish doctors**

By [Daily Mail Reporter](#)

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On Tuesday night, a well known figure walked into St. Vincent's University Hospital in Dublin.

Clutching a small overnight holdall, the man in the smart suit and dark navy overcoat quietly made his way to his room. Unlike the hundreds of ritual hospital visits that have formed part of his cancer treatment to date, this one was different.

This one was a gamble.



Trust: Tommie Gorman is trying the Irish health system after 19 years of treatment abroad

For almost 20 years, Tommie Gorman, one of RTÉ's top broadcasters, has fought and managed a heroic battle with carcinoid cancer.

Since 1998, four years after he was told he was suffering from a rare hormone-producing form of the disease, that battle has been fought in Sweden, a place where hundreds of Irish 'medical tourists' such as Tommie flock for treatment.

Now, having so long shunned the Irish system for the more advanced Swedish model, Tommie has decided to put his life in the hands of Irish doctors and the maligned HSE.

It is a decision that marks the end of twice-yearly visits to Uppsala in Sweden, leaving behind the familiarity of doctors he knows and trusts and a system that has kept him alive far beyond initial exceptions.

Carcinoid cancer – or neuroendocrine tumour (NET) to give it its other label – is rare but it boasts some high-profile casualties. Dublin TD Jim Mitchell, who had a liver transplant in an attempt to beat it, died in December 2002.

More recently, Apple founder Steve Jobs, who had an NET in his pancreas, lost his long battle too.

Tommie Gorman has defied the odds but he is aware of how precious his time is.

'You are very conscious that you won't run the normal course,' he says.

'You are planning what you are going to do for the next X number of years. But here I am nearly in 2013 able to talk, which is an absolute miracle, given what I was told in 1994. These are the grace note years; these are really special times and there is a fantastic feeling of gratitude and appreciation that I have had

this amount of time.

'Our son wasn't born when I was diagnosed. My wife made a very big decision on those kinds of matters and sometimes you become conscious, you know, like if you are in a car and the fuel tank isn't working and you are driving, wondering where the next filling station is... it's like that. These are all good years.'

Regularly seen on television screens looking fit and healthy, off-camera the father-of-two has allowed the Swedes 'to do what they want' to try to stem the progression of the disease. Over the years, his 56-year-old body has run a gruelling gauntlet of invasive surgery, radioactive therapy, drug treatment and sustained probing and prodding.

At his home in Belfast, where he works as RTE's Northern editor, he is warm, friendly and eager to talk. The kitchen table in the large Victorian house is strewn with notebooks and papers. Beside a neat pile of notes is a dictaphone and a box of medication. He makes tea and shares out some chocolate.



Bright side: Tommie Gorman has remained unfailingly optimistic

'Do you see that holdall there on the floor?' he says. 'That's packed for me to go into Vincent's for the first time tonight. I'm putting my money where my mouth is.'

It's a brave decision, because by no means everyone in the Irish health system was happy with his decision to go to Sweden in the first place. A 2001 fly-on-the-wall documentary, *Cancer, Europe And Me*, that chronicled his attempts to halt the spread of the tumours in his body, provoked annoyance among the medical profession here.

Tommie discovered that he was entitled as an EU citizen to be treated in Sweden on the basis that the treatment was not available in Ireland. A quote in the documentary, 'medicine and money... oil and water... they don't mix' went down like a lead balloon with Irish medics, as did Tommie's revelation that the senior endocrinologist in Sweden was earning a fraction of what Irish consultants were paid at the time.

'When I did the program in 2001 there was a hostile reaction from lots of Irish doctors,' he recalls.

'They wrote in to papers, saying, "Why is he going to Sweden? He can get everything here." I make no apologies about it. The truth was that the system wasn't sufficiently together at that stage.

'In the years since, I have had lots of contact from Irish doctors who have talked to me about my disease. They came to me and told me about what they were trying to develop and I agreed that if they needed my help, I would be more than willing to put my trust in their hands – if and when they had the Irish system in a fit-for-purpose shape .

'We are now at the stage where I think the structures and expertise in Ireland are sufficiently developed for me to put my faith in the system.'



TYRO: A young Tommie Gorman interviews Mgr James Horan as the first flights take off from Knock Airport in 1985

It's a judgment call – and the stakes are high. But there will be advantages to being treated at home – no more twice-yearly 3,000km round trips to Sweden.

Nor did it give him any satisfaction to admit that hitherto the Irish system simply wasn't up to scratch.

He is, after all, a proud Irishman – Sligo born, bred and educated at the local Summerhill College before moving to Dublin to study journalism in the College of Commerce, Rathmines.

Then it was back to the northwest to begin his journalistic career in the Mayo-based Western Journal before becoming RTÉ's northwest correspondent in 1980. In 1989, he moved to Brussels to become Europe editor before taking up the post of Northern editor in 2001.

The family home, which he shares with his wife, Ceara, and two children, is near Strandhill in Sligo.

He commutes to work in Belfast. He is on the management committee of Sligo Rovers, the board of management of the Ursuline College and the fund-raising committee of Summerhill College. So he is deeply rooted in and committed to his community.

But as fate would have it, his illness was diagnosed back in January 1994, while he was living in Brussels and working as RTÉ's Europe correspondent.

'I was very young when I was diagnosed – 37,' he says.



Brave: Apple founder Steve Jobs lost his battle to NET

'The worst time for anyone with cancer is when you are told, because it's like Armageddon. Then it gets a little calmer after that and you try to cope with it. Then you start to try to deal with the circumstances you face. Personally, the only bad time was when Ceara came into the hospital. She obviously didn't know and I had to tell her and that was heavy... because I knew what I was facing into.

'We were based in Belgium and here we were, nine years married with a 10-month-old daughter and cancer.'

Tommie was diagnosed with having a midgut carcinoid with tumorous cells spreading to the liver and lymph nodes. In the same year, the primary tumour was removed by keyhole surgery in Brussels.

'They said, I had a primary in my midgut,' he says.

'They had another problem in my mesentery area and then he said you have some spots on your liver as well. So liver and cancer was pretty heavy stuff. Then the doctor started talking about survival rates.

'The survival rates in 1994 for somebody with my presentation of the disease were about 50%. You got five years and after that all bets were off. I remember the doctor saying, "And who knows, you could be one of the exceptions. You could live for 15, even 20 years." So that's 19 years ago.'

After initial surgery and four years of monitoring in Belgium, a doctor friend from Sligo advised Tommie to consider a more pro-active approach to his treatment.

Drawing on his journalistic instincts, he then took to the internet and began researching his disease to find out where the best place for treatment was. 'That's when I found the Swedes,' he says. 'I discovered Sweden was a world centre of expertise in this area and that they knew exactly what they were dealing with.

'From then on, it was a question of how do you get into that system. And through my EU stuff, I discovered the E112 system – and I have been going back ever since.'

In April 1998 the Swedes put him on a course of interferon, heavy-duty chemotherapy three times a week. He also received a monthly injection of sandostatin to counteract the effects of the hormones his cancer produced. Then, in 2008, he received four treatments with lutetium-octreotate, a radioactive isotope

sourced from a nuclear plant in Rotterdam.

'I got four belts of that,' he says. 'That was heavy duty, cutting-edge stuff. That's the most a liver could take because I would have wrecked my kidneys if I had got any more. So that was radioactivity coming into the system.'

'It was like something from Star Trek. They would come in in all these suits and they took out this stuff and they put it into you and they would leave you to absorb it. They isolate you in a room, push in your food and keep their distance.'

'When you come home, you need a special form for the airport because when you go through the security things you are radioactive. But the effects were a bit like make-up... they wore off after a while. It works for a lot of people but unfortunately I didn't get great results from it.'

Due to progression of the disease in the liver, he underwent radioembolisation in February 2010. This involved going in with a prong with tentacles and applying a charge through the prong to burn off the tumour.

'That was another thing that the Swedes were able to do that couldn't be done here,' he says.

'After the radioactive treatment, a lot of the tumours went quiet. But there was one that didn't... it took courage from the assault and began to grow. So they did a thing called radio frequency ablation on it. It was even better than the other stuff because I could feel the benefits.'

Still, after years of sustained physical warfare inside his body, the battle continues. Carcinoid cancer, which affects around one in 100,000 to 150,000 people, is an advancing disease that can never be totally eradicated from the body, only slowed on its tracks.



no rest: Gorman spent eight weeks at the Michaela Harte trial in Mauritius

'I now have in the twenties of tumours on my liver,' announces Tommie.

'They can't take them all out or burn them all off because your liver would end up like Swiss cheese and it wouldn't function properly. You can't replace the liver because it has been tried with a few people with disastrous results. With a carcinoid patient, somebody like me, the medication I take is to boost my immune system.

'If you give a person a new liver, to get it to match, you have to switch off the immune system to let it take root. This allows the carcinoid to go crazy.'

Since the documentary, Tommie has quietly and discreetly continued living with cancer behind closed doors.

Despite his high-profile career as one of RTÉ's most recognisable faces, he is intensely private and guarded when it comes to his family, particularly his son Joe, 16, and his daughter Moya, 19.

He points to a framed portrait in the living room that shows him and his son on a mountain top in Sligo. He says: 'My family just love me. They know the story – there is nothing held back. You put your faith in love and get on with it.'

'We are private people, shy people. I'm a reluctant celeb and Ceara is very private.

'Being here in Belfast and having that element of distance is no harm. I have always said that me being away so much gets them used to the notion that I'm not an ever-present figure. That's deliberate.'

But the bid to stay one step ahead of cancer is physically and mentally draining. There is the constant worry and anxiety for both the patient and his or her extended family and the fear of not knowing what is coming next. Despite all of this, Tommie is unfailingly optimistic when it comes to the hand he has been dealt.

He insists it isn't a facade but admits that two years ago he was close to giving up.

'There was one time,' he says. 'It was after the procedure where they scoured my liver with acid. First of all when, I was on the table, I got a carcinoid attack. The tumours are like barking dogs. This stuff was coming at them aggressively so in response they sent a whole lot of hormones through my system and they nearly lost me on the table. They had to pump stuff through me to get me stable.

I was chatting away and then I couldn't talk. In that procedure to fix me, infection got into my system.

The weekend after, the pain from the infection was excruciating and that was the only time when I said, "Maybe I should sign off here." The pain was just so bad. When they found out what the problem was and the nurse squeezed all the pus out of the wound... the relief from that! Well, the world turned again.'

Part of his strategy is to absorb himself in his work. In the summer, the veteran broadcaster spent eight weeks in Mauritius covering the Michaela Harte trial, missing one of his biannual visits to Sweden.

'Work is a fantastic distraction,' he says. 'It is vital. Some people might want to take it easy but, for me, work is a form of therapy. If it ever got to the stage where it was affecting my work, I would have to walk off the stage quietly. No big drama, no big fuss. But I'm not at that stage.

'If you think of where I was in 1994, I have been so lucky. You make deals. When somebody says you could get five or 10, you think, "That's brilliant." When you hear 20, you think, "Wow!" But when you are in year 12 of that, you start thinking, "Is that little pain or whatever the beginning of something different?"'

One such deal Tommie has made is with the doctors behind a brave plan to treat patients with his disease here in Ireland. Some of the doctors who criticised his 2001 documentary have since sent patients to Sweden to avail of the treatment he had received.

In 2007, Professor Donal O'Shea, consultant endocrinologist at St Vincent's, came to him with a proposal. He planned to implement an Irish version of the Swedish model that would involve the Irish integrating with the Swedes when they need to.

Part of his plan was to ask Tommie to come on board and put his faith back in the Irish system. At the same time, patients in Ireland were asking the RTÉ reporter for advice on where to get treatment in Ireland.

'We carcinoid cancer sufferers met in Cork for the first big gathering last year,' he says.

'The Swedes came over as well. Doctors from here were able to see a group of people with the same disease and they could hear from them at first hand. It was a big moment. So we decided to launch our own support group that can meet every year and try to influence the system. To coincide with that, I decided it was time to have a cut at the Irish system and see how it was working.'

Having missed his June visit to Sweden, Tommie also decided not to attend an appointment scheduled for September.

Instead of packing his bags and heading to the airport, he drove himself to Dublin this week. His agreement with the Irish doctors who are now looking after him means he no longer has to leave the country.

However, the deal comes with a caveat – if the Irish system can't provide the service, doctors here must refer him back to the Swedes.

'I'll be the first one to speak up if it isn't working,' he said.

'When it's a question of your life being on the line, you are entitled to do that – but I'm willing to give it a go. The Swedes have kept me alive up until now and I'd be dead and buried and forgotten without them. But, over the years there have been doctors in Ireland who have been conscious of people like me, trying to help people like me and trying to put the structures and systems in place to do that. I'd love if in the course of my life things will get to the stage in my own country where this is in place.

'I think we are there now – but give me 12 months and I will tell you if I'm right.'

The launch of the patients' support group Network takes place in the Long Room Hub in Trinity College, Dublin, on Saturday, November 10.

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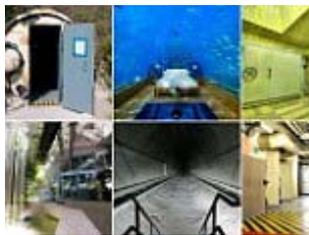
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