

# Patient story: Mouth cancer

## Brian Elias

KILLING  cancer

## How PDT saved Brian's life 17 years ago

Composer, Brian Elias, talks for the first time about his brush with cancer, and demands to know why, 16 years after his successful treatment with his chosen therapy, it is still not being offered to patients across the whole NHS.

"When my surgeon, Colin Hopper, invited me into his treatment room at Mortimer Market off Tottenham Court Road in London, and told me what he planned to do, I think I probably laughed. Was this really part of University College Hospital?"

"That was in August 1992. Apparently, I was to be his 18<sup>th</sup> patient – the 18th person in the whole world – to be injected with a light-sensitive drug, and then he was going to shine a light on my mouth cancer. I thought the whole thing quite improbable, and it seemed like Star Wars, gone mad.

"It didn't help that, when I looked around his tiny treatment room, it resembled an untidy radio ham's workshop. Was this really where a ground-breaking medical treatment was starting its life?"



"The treatment I received is called Photodynamic Therapy – PDT. The injected drug apparently makes the cancer sensitive to light at a particular frequency, and when it is shone the cancer cells they die because the drug and light reaction stop the oxygen in the blood getting to the cells, leaving all the healthy cells completely unharmed.

"Over the next two weeks, the skin in my mouth healed completely. I have no radiation burns as a result and today you would never know that I've ever had a problem.

"Having kept in regular contact with Colin ever since for my annual check-ups, I can tell you that the treatment room looks exactly the same, although the machines he uses now are somewhat smaller and look more hi-tech.

"But sixteen years ago, I really did feel as if I was taking part in an experiment that stood the risk of going horribly wrong. That room. That building. It isn't a place that inspires any confidence!

"The funny part about it is that Colin still sees his patients there, and they still have the drug injection in the same, pokey little room. He tells me his patient numbers are now up to almost one thousand, and I bet they all had the same thoughts as I did.

"My cancer was inside my right cheek. I have no idea what a mess they would have made of me if a surgeon had been allowed to carve me open. I'm told that the cancer was pretty serious, and it would have been touch and go whether, in those days, it could have killed me if left for very much longer.

"So, yes, it was serious, but even in those days when Colin Hopper had more hair and I had more youthful looks, I trusted him entirely and believed totally in what he was proposing to do. I don't think I even gave more

than a second's thought to ask whether numbers one to 17 on the trial were still alive. I just assumed they were.

"Asking today, I'm told that most are, and those that have moved on got other cancers or died of natural causes.

"So, I was a guinea pig. It took just one treatment to fix me up, and the fact that even now nobody knows I had dived with cancer, is entirely down to the treatment and how effective it was.

"I guess that I couldn't have kept my cancer a secret for all those years if there had been a hole in the side of my mouth. That, I'm told, was the other main option, and they would have patched me up with skin and flesh from other parts of my body.

"At the time, I remember Falklands man, Simon Weston, saying in an interview that his face had been rebuilt and that his nose was actually a piece of his backside. I didn't really fancy something like that.

"The fact that I was number 18, and that I am so clearly alive and well today, does amaze me when I stop to think about it. No, I'm not astounded that I am still alive, just immensely grateful. But I simply can't believe, that in all of those 16 years the NHS hasn't made it a priority to make sure that this incredible treatment is available right across the NHS. Instead, it is still, almost exclusively, only available from the same man.

"What is the NHS playing at? Apparently, PDT for head and neck cancer treatments is still little more than £4,000, and that surgery for a cancer like mine – with all its scars and discomforts – could easily be more than £20,000. All of my treatment was done on an out patient basis (including the first biopsies, the injection of Foscan, the PDT itself and subsequent biopsies) and apart from a little facial swelling which lasted two or three days, I was fully recovered within 10 days.

"In fact, the worst inconvenience was having to stay indoors for a few weeks, or to cover up extensively (hat, scarf, gloves) if I went out, to avoid getting burned as the treatment at that time left me extremely sensitive to light.

"Now the drug has been developed since my experience and the extreme light sensitivity now only lasts for a few days.

"So, why am I telling my story, 16 years later? It's because I am angry and frustrated. I had a close friend of mine die only recently. One had surgery for something called Barrett's oesophagus, and never even made it home from the op. PDT has been able to treat Barrett's with the same, incredible simplicity, for years.

"And I hear of people who have also had mouth cancer – similar to mine. They look a mess. They can hardly speak because surgeons may have cut out their tongue, ripped teeth, and generally destroyed their faces.

"I can't tell these people that I was treated with an experimental treatment all those years ago, and that I can still eat and talk normally, and that they could and should have been treated the same way? It's all down to the people running the NHS.

"If you or a friend draws life's short straw and end up with mouth cancer, you will be one of 7,500 people a year who do. If you want my advice, I suggest you contact the Killing Cancer charity who will do their best to find you a PDT expert."