

Operation and Immune Therapy



Back home after the operation, [@Henning Vigold](#)

Operation

At the beginning of February 2003 I was diagnosed with renal cancer in the left kidney. Quite quickly something was done about it, on 20 February 2003 my left kidney was removed. Apart from being somewhat exhausted after such an extensive operation, I felt fine, and was told that they believed they'd got it all.

Control

In May 2003 I was scanned, and the result was 'not quite acceptable', so they wanted a biopsy. The next few months were a bit chaotic in this regard with the wrong scans being done and unusable biopsies, but the result was that they managed to get a biopsy in October, which didn't show anything unfortunately, and at the beginning of November I received a letter which stated that it was probably 'just a bit of intestine', so everyone could just calm down. Everyone that is, except The Mysterious Mr. Mox, who continued to grow quite merrily.

Immune Therapy

Towards the end of March 2004 I went to the ordinary control. But it was not at all ordinary. The Mysterious Mr. Mox had grown quite a bit as it turned out, so it was decided to do another biopsy. I was sent to Elsinore Hospital, and this time there was no problem seeing the tumour or taking a sample from it. Then I was referred to Aarhus Municipal Hospital (AKH), where they did something called Immune Therapy. After one more CT scan, this time of my head, since metastases up there would make me ineligible for the treatment, and a goodbye session at work, I was ready. And a few days after I went to Aarhus to try Interferon.

Interferon

I moved in with some friends in Skanderborg. During the first week, week 0, you turn up at AKH on Monday morning. After a couple of hours you are allowed to molest yourself by injecting a dose of Interferon. Which I did, and my friend from Skanderborg, who works in Aarhus, picked me up early in the afternoon, and drove me home to her place by way of the DIY store. The trip to the DIY was because I needed a cold store, because the medication is ruined by heat. During the evening the fever shivers started, and I had to sit with a duvet around me, until I was groggy enough to go to bed around 10 in the evening. Tuesday I returned to AKH, had a new dose, and we agreed that I didn't need more tuition in self-injecting, so I took the train home. And enjoyed myself the rest of the week with my daily injection, my shivers, my nausea, and so on.

Interleukin

The next week I went back to Aarhus. This time I travelled on the Sunday afternoon, because I had to turn up at 9 a.m. at AKH. I and my wife took the train together to Skanderborg, had a cozy visit with our friends. Monday morning, i.e. at the beginning of week 1. we had a conversation with doctors and nurses, it was the first time Birgit came along. And I gave myself another shot, this time Interleukin. Birgit and I went for a walk in Aarhus, and then she took the train home, and I went back to AKH. By late afternoon I took the second shot of Interleukin plus a shot of Interferon; I was getting started on week 1. I returned to Skanderborg by Falck (ambulance service), and again used them to get to AKH next morning. Here they agreed that I could go all the way home, and ordered transport for me, something I didn't even know was possible. Late on Tuesday morning the transport came from Zealand to fetch me at AKH, something I was going to get quite used to.

Weekdays with Immune Therapy

Week 2 was no different from week 1, except that I didn't have to spend the night in Aarhus. I fetched the medication on the Monday, rang for transport myself, and they came and picked me up. I then got Interleukin for the full week, and Interferon for the next three weeks. The Interferon I was supposed to take all the time, except for weekends, but it keeps longer than Interleukin. So week 3 and 4 were 'only' Interferon, and that is much milder, or so they told me. And that was the routine, first week 0, then week, 1, 2, 3, 4, 1, 2, 3, 4 For six rounds to start with. And if

the scannings after six and again after 12 rounds show bad results, i.e. if The Mysterious Mr. Mox has grown, then you stop, otherwise you continue. And after the 13 rounds you stop completely. If it starts growing again, you reconsider your options.

Goodbye to Interferon

But next time I reached week 1, things began to go wrong. I shivered all the time, and felt really dreadful, even though I was only on Interferon. Of course it had to happen during the one week of my wife's holidays, when we were planning a couple of car trips around the countryside, where we could imagine that our lives were normal. On the Tuesday I consulted my own GP, who contacted AKH. The result was that on Friday we went to Aarhus, where they took a look at me, told me to get a couple of bags of blood, which of course had to be given in Hilleroed, back home. When I got home shortly before midnight (!!), I felt quite good. But my dear wife insisted that take the Interferon, after which I was completely worn out again for the duration of the weekend. And on the Monday, when I went routinely to Aarhus again, the doctors 'sentenced' me to say goodbye to the Interferon. The rest of the time I was unmedicated for weeks 3 and 4.

Allergy

One day in November right after lunch, and three days before the full treatment finished, my tongue began to feel too big. It swelled and swelled, and so did the chin. I went to my GP even though he would rather have sent me directly to Hilleroed Hospital. I ended up at the hospital in an ambulance anyway, but at least without the siren going. I had developed an allergic reaction. It was agreed that it was probably a reaction to the Interleukin, even though I'd been taking the stuff for five months. And since there were only three days left of the treatment, it was stopped immediately. I had been longing for the day the treatment ended for half a year. And then when it did stop, I felt terrible. The allergic reaction began to subside while I was awaiting the doctor at Hilleroed, and next morning I just went home.

The Final Scan

One Thursday in December I was due for my final scan. I wasn't the least bit nervous, everything felt just fine, so once again I went by VIFA transport to Aarhus to be scanned. And the most important problem was the stomach, which now objected to the contrast liquid.

The Result from the Final Scan

After the scan I wanted to feel well for once. We had earlier taken part in a number of hikes with other dog people, and on Saturday there was one going on. And we went on the hike. It was a bit hard, and the weather turned out not quite so nice, as when we started, so when we returned to Ballerup Station after a couple of hours, I was cold through, my feet were wet, and so on, just what one shouldn't do. On the Sunday we participated in the Christmas Party held with the small group which constitutes Roskilde Country Show Cat Exhibition Committee. I was shivering a bit, but I'd been

doing that routinely over the last six months. On Monday I went to work. There was an important discussion I wanted to participate in, and where I thought it important to state my opinion. I did that, supported by others, and it made no difference, by the way. And then I went to Aarhus on Tuesday 21 December 2004. Unfortunately The Mysterious Mr. Mox had grown. A lot or a little didn't matter, it had grown. At AKH they were running a clinical trial, and another one was running at Herlev, and since the doctor couldn't recommend one over the other, he proposed I try Herlev, since it was so much closer to home. The next day, Wednesday 22.12, I went to my GP. I was running a temperature and shivering constantly. He listened to my lungs and sent me to be x-rayed. Unfortunately the x-ray machine was not functioning, but now my temperature was over 39C. My GP made a house call in the evening to have a look, gave me a shot of penicillin and a prescription. Next morning the temperature was still there, only now between 40C and 41C. And so it came about that I was hospitalised just before Christmas on 23 December.

After the Immune Therapy

Christmas in Hilleroed

My stay in the ward at Hilleroed started well with the whole ward being closed down because of a tummy bug!! I just managed to get admitted and infected, before all new admittances were stopped. And apart from that I lay there with a drip and penicillin for the next many days to get the fever under control. Christmas Eve and New Year's Eve I spent at the hospital, but the weekends between them I spent at home. The first weekend only briefly because the temperature rose again. Finally one of the doctors decided that all the antibiotics didn't help. So she took me off them, and from then on I made progress. In the meantime contacts to the clinical trials in Herlev and Aarhus had been established, but both turned out to be dead ends. The trial in Herlev rejected me because of my allergic reaction, and the trial in Aarhus rejected me, because they had closed for new patients. Both suited me quite well really, for I wasn't really sure that I wanted to try any sort of immune therapy ever again. No matter what the consequences might be. And at the beginning of January I was discharged, and could go home again, if somewhat weakened.

Back Home

In connection with my stay at the hospital a lot of useful paperwork had been done. A request had been sent to the Health Authorities for a 'certificate of terminal illness', which ensures free medication to terminal patients. It arrived a few days later, and made it slightly less irritating to go to the pharmacy. Contact was established to the municipal home nursing office, and for the next many months they visited weekly to see if I needed anything, which was a very reassuring arrangement. I had been given information about hospices, and contacted St. Luke's Hospice, who shortly after sent someone to visit me, and without hesitation approved me for their future services, when that should become relevant. And by way of St. Luke's I got into contact with the palliative team in Hilleroed, from where I (and my GP) got a lot of help to improve the treatment of pain and nausea over the next months. But this does not imply that life was easy. The daily fight against the nausea at mealtimes took a lot of energy. I had to pull myself together when lunch or dinner time approached. Some days it worked, and some days the food did not stay down. It was especially bitter, when you felt that the very last bite was what triggered that it all came up again. If you'd only spared yourself the ambition to eat up, then there would have been more nourishment in the tummy, than was actually the case. Pain was generally not so big a problem. But some experimentation on behalf of my GP was required, helped along by the nurse from the palliative team. And not always with the greatest of luck. I tried morphia tablets and did not do well on them. I tried morphia plasters - lowest dose, 25 μg /hour. I put it on on a Saturday morning. By Sunday morning it began to work both for good and evil, and I very quickly pulled it off again. And Sunday we visited my in-laws for lunch. Where I spent most of the time lying on a sofa. I managed to keep down the food, which was not the case with supper at home that night.

At Work

I wasn't feeling well, but very slowly I got some energy back, and could begin to visit my place of work. Sometimes for a few hours every other week, sometimes most of a day, twice a week. Getting food served in the canteen was very good for my appetite. Probably this was purely in my mind, but those days were anyway considerably easier to get through. So until the end of May I went to work more and more, at times so much that a few people thought I was back full time. Which was definitely not the case.

Social Activities

We could begin to have visitors. We couldn't quite manage dinners, but a cup of tea and some cake had definite value. And during Easter we were invited to a 70th birthday at some friends' house nearby. I carried it through. Some of the cake came up again, but I am fairly sure that dinner stayed down, so both socially and with regard to the nutritional value it was a good event.

But Then

But from the end of May it began to go downhill. I couldn't manage going to work anymore. A visit to friends in Aarhus was cancelled at the last minute, because I simply couldn't face the drive over there (3½ hrs), even though I wasn't driving. And when I was contacted routinely by St. Luke's by mid July, and they asked how I was doing, I had to admit that I really wasn't doing very well, and that maybe this was the time to move to another address.

Hospice



Home again from Hospice, [@Henning Vigold](#)

Hospice

The first couple of weeks at St. Luke's Hospice I improved quickly. While my GP and the nurse from the palliative team worked by trial and error to alleviate the nausea and pain, the efforts of the doctors at St. Luke's was much better targeted and was carried out with much more certainty, and after only 3 to 4 days, I felt fine, could take walks and go home for the weekend. But it only lasted until the second weekend. It started quietly enough. I went home Friday night, Saturday afternoon some friends were coming to visit, and while we were talking of this and that, I suddenly began to feel really bad, lots of abdominal pains and had great difficulty in concentrating on my visitors. I still managed to cook dinner for both of us. But after we'd gone to bed, my sleep was very troubled and noisy, and so my wife went down to the guestroom in the cellar to get some sleep. So that when I woke early in the morning with violent pains, I was quite alone. The first couple of hours I just stayed there. I tried to call, but it had no effect. And about 7.30 I needed help and managed to crawl down the stairs and wake my wife. After a couple of hours it became clear

that I had to get to the Hospice. They would contact one of the doctors, even though it was their day off, and early in the afternoon we drove back to the Hospice.

Ulcer

The doctor quickly brought out her serious countenance. The diagnosis was a perforated ulcer, and she estimated that I might not last the night, even though they put it rather more delicately to my wife. She contacted her brother and a couple of close friends, went home to see to the animals, and then came back and stayed the night at the Hospice. Next morning I was still alive, but I was sentenced to 'nil by mouth' and a drip. And I continued like this for the next couple of weeks, getting thinner and thinner. After a week I was allowed an ice lolly, and after another week I began to eat real food, but very slowly. But I was undeniably very weak. People came to visit and drove me round the park in a wheelchair. I got so much better that I could go home one afternoon by Falck (ambulance service). My wife and a couple of friends took me on an outing to The Tivoli Gardens in a wheelchair, and it was quite entertaining all of it. Later I got well enough to go home for the weekends, and slowly and quietly I became stronger and stronger. Walking up stairs took some time, but I improved in that area too.

New Scan

In the middle of October the doctors felt that it was remarkable how well I did. One thing was recovering from the ulcer. But starting to go to work again sometimes. And well enough to go home every weekend, that was not what was expected from a patient with a terminal prognosis. And so they suggested that I had a new ultrasound scan done. This I thought was an excellent idea, for I had begun to think that I was feeling much too well to stay at a hospice. The ultrasound scan still showed tumours, but when they were compared to the CT scan from December the previous year, they looked smaller. And the largest tumour, which previously could easily be felt and at one point could even be seen, this could no longer be felt, not by me and not by the doctors.

CT Scan

Considered as a cancer patient I still belonged in Frederikssund, and they took a look at the ultrasound scan and compared it with the old CT scan. They thought it looked so unusual that they ordered a new CT scan at the beginning of November. And a couple of weeks later, my wife and I went to an interview at Frederikssund Hospital about the result of this scan.

The Miracle in Hellerup

The Consultant in Frederikssund looked completely confused at this interview, to put it mildly. Confused in a happy way, but still confused. For something like this he had never seen before. The large tumour had disappeared. But just as odd was the fact that all the metastases were subject to central decay, i.e. a situation where the tumours become like water in the middle. He explained to me that this is often seen in cases of renal cancer, but only for the original tumour, never the metastases. And

yet this was what had happened here. Already before this interview I had decided to be discharged from the Hospice, for no matter what they said, I felt too well to stay there, whether for 3 months or 30 years. But since the interview went as it did, there was no disagreement about this from any source.

Withdrawal

What's left now is the withdrawal from the rather large doses of painkillers and prednisolon. That may happen over the next period of time. Right now I can say that I am, if not well, then well enough to play well, make do with quarterly CT scans, and enjoy the fact that the Hospice for once can register a discharge of this kind.

The End

Henning's general well-being continued well into 2006. There were a few serious pain attacks, and a couple of flu-like fever attacks, but he went to work, worked from home, and we had a new litter of kittens, which he enjoyed looking after. I, Birgit, went so far as to plan to bring home a new puppy, something I'd wanted to do for a long time.

In February the doctor at St Luke's Hospice contacted a specialist at the State University Hospital who wanted to talk to Henning. Partly about his present unusual condition, and partly about a new, experimental treatment of 'local chemo', which they had begun to offer at Aarhus Oncological. A new CT scan and a PET scan were done, and the results were mixed. There was still growth in some of the metastases, but Henning's outstanding well-being meant that he was recommended a trip to Aarhus. The initial interview was set for 12 April.

At the same time the professor recommended that Henning cut back on the amount of Prednisolon which he took daily, and which was an important factor in his well-being.

I fetched home our new puppy on 18-19 March, and in the following week Henning began to turn down the Prednisolon dose, but he quickly got worse, and restored the Prednisolon dose after 3 days. On Saturday 25 March, he developed very strong abdominal pains, and we called a doctor who hospitalized him immediately at Elsinore Hospital. He had asked to be admitted to the urological department at Frederikssund Sygehus, because that was where his disease belonged. He rang home and asked me to bring his normal painkillers because the hospital pharmacy didn't have it in stock. They only had morphine which he had problems tolerating. I brought all his palliative medication the next day. Unfortunately the doctors at Elsinore Sygehus didn't know his medical history. Sunday he still suffered very bad pains, Monday he began to be very hazy, unable to hold on to a glass of water or a mobile phone, and it culminated on Wednesday morning, when he went into a coma. He was given an 'antidote' to the morphia, after which he became a bit more clear-headed, but he was still very much in pain.

On the Tuesday they had done another CT scan, and on Wednesday the doctor presented us with the results. That the cancer had spread was hardly news. That Henning's medication was immaterial according to the doctor surprised me. Anyway, Henning was due to be moved to a non-urgent medical ward, and as St. Luke's didn't have an empty bed, he was moved to Frederikssund Hospital. When I packed his things I could see that all the medication which he had brought with him, had remained untouched, and I asked the nurse, if they had ensured that he got the normal medication according to the dosages set out by St. Luke's Hospice. The answer was: No, he wanted to control that himself. Henning then asked for the Prednisolon, and when he was arrived in Frederikssund, I got hold of the nurses there and made sure that they got him started on all the right medication. However, by then the damage had been done.

At Frederikssund he got his 'normal' medication, but no more, i.e. he was never without serious pain. He was seen by a specialist from the department for palliative care which was right next door to the urological department, however the specialist decided that he was too ill to benefit from further palliative care. This I did not discover until I got Henning's records after his death.

On Friday 31 March St. Luke's Hospice contacted Frederikssund Hospital, and asked if he wanted a bed there. On his behalf I said yes, even though he thought that it wasn't necessary, he only needed his medication stabilised, and then he could go home. Saturday 1 April he had very strong pains and he was repeatedly x-rayed to check if the passage through the intestines was ok. Sunday saw some improvement in the pain, but he was very depressed and weak.

Monday 3 April he was told that there would be a bed at St. Luke's Hospice from the following Wednesday. And everyone breathed a little more freely. He asked me to bring his computer to St Luke's so he could use it when he improved a bit.

Wednesday morning he was taken to St. Luke's Hospice, where I arrived half an hour later. Already when I looked in on him it was obvious that he was much more relaxed than he had ever been at the hospitals, where he was disoriented because of the many moves between rooms, wards, and hospitals, where the communication was minimal, where it took 15 to 20 minutes for a nurse to respond to a call, and where he was constantly afraid of what was happening to him. And for the first time since he was admitted to hospital he was completely free of pain.

His 'favourite nurse', Bente Clausen, was on the day shift when he came, and even though he didn't say much, and he quickly got worse and worse, it was very clear that he felt safe and at home. And it was a great help for those of us who came to visit that he never had to wait for help, when he needed it.

Sunday morning I got a phone call from Bente, who thought I should come as soon as possible. I had to change my clothes and feed the cats and dogs, and unfortunately Henning died before I arrived.

I know he died peacefully and that he felt secure, and afterwards I got all the time alone with him that I could wish for.

Bente and his best friend throughout the whole business, Jeanet, laid him out, and said their farewells to him in this way.



After Henning's Death

During the months after 9 April 2006 I gathered together the records from the different hospitals. I wanted to understand how Henning could have deteriorated to badly at a time, when no one expected his death, but quite on the contrary expected him to start on a new treatment which had a good chance of giving him some more time and keep the cancer at a distance.

As a result of what I read in the hospital record I lodged a complaint against the hospitals in the Patienklagenævn in October 2006, and later on I also reported a claim against the health system in the Patientforsikring in the beginning of 2007. I did not do this to try to bring Henning back, but because I wanted to prevent others from having to go through the same hell that Henning had to live through in the last two weeks of his life.