



Dr. Derek Suchard

Things I learned from Jeroen

Netherlands UU Fellowship

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Back in July, many of you will remember, we gathered, along with some out of town visitors from other EUU fellowships, the Women's Group, and Taco Ijzerman, in the Flevopark on July 6th to celebrate the solstice. It was cut somewhat short due to rain, but was still nice to be able to get together for a less formal activity. Less formal, but not less spiritual, however. We witnessed, for example, the dramaturgical battle between the Holly King and the Ivy King for domination over the second half of the year.

Unsurprisingly, the Holly King won, and is now in charge until the battle is once again joined in December. Betting on the outcome is now open at Betfred locations everywhere, and I have a good inside line, if anyone's interested.

During the reign of the Ivy King, or, for those who prefer a Greek touch, while Persephone is in the underworld in a story that -- on reflection while writing this yesterday -- closely resembles the story line of the Phantom of the Opera, Beauty and the Beast, and some less pleasant real-life stories, too, while Persephone is in the underworld, nature retreats into itself. Plants stop growing, fruit is unavailable. It is, to coin a phrase, *une petite mort*, a little death.

It has always struck me as somewhat ironic that our service year begins at a time that the meteorological year is winding down in the northern hemisphere. So we are trying to strike a balance between beginnings and endings.

Normally, the emphasis is place on the beginnings, quite understandably. This year, though, I would like to shift the focus ever so slightly, and talk about something that is less about fresh starts, and more about sudden endings.

Jeroen was a schoolmate of our son Benjamin during his primary school years. They were very close, and Jeroen was often a guest at our house, just as Benjamin was a frequent visitor at his.

Jeroen went with us on some very memorable holiday trips, such as a week-long stay at a prehistoric village in Eindhoven, where we all had to live as if it were the year zero in the Netherlands. So restricted diet, no citrus, or coffee, or tomatoes or potatoes...no wonder the Europeans went a-colonising...the diet alone would have been sufficient incentive. And to those who think I exaggerate, remember, Columbus and Vasco da Gama had two things on their to-do list when they went exploring....1. convert the infidels (by force, if necessary) and 2. Bring mamma some spices for the kitchen. Not necessarily in that order.

But, I digress.

Jeroen also accompanied Benjamin and me on a trip to Egypt in 2001... As part of a group tour, we formed a small band that we referred to as Strike Team Hoofddorp and had adventures in horse-drawn carriages, in haggling in the market, and eating strange food products as we travelled by train and bus from north to south.

I have learned a lot from Jeroen over the years. Starting when he was still only 10 years old when we went to the prehistoric village. Because we had to live like period people, we had to wear simple clothing. And we were living more or less outside in an environment where we

were constantly working with clay and mud and chopping and cutting and what have you. And that's when I learned that it's possible to live like that and still remain spic and span clean. Even after a week, Jeroen didn't have a speck of dirt on his clothing or his face, despite having been as active as the rest of us, he looked like he'd just stepped out of Prehistoric Gentlemen's Quarterly. Unbelievable.

I also learned a fair bit about communication from Jeroen. Not that he was a great orator or anything. But the clarity of my communication became much sharper thanks to communicating with him. It had to. He didn't process information the same way, so it had to be presented very clearly.

Jeroen was diagnosed at a very early age...5 or 6, I think...with Asperger's syndrome, which is on the autism spectrum. And he spent a lot of time on the computer, playing games of various kinds. He was very computer literate at a very early age. So we talked a lot about computers. He also had a great fascination for zoology and his pets over the years included rodents. One day, he came to us, very upset, in tears almost. His mouse had died. Not making the correct leap, I understood him to be complaining about the failure about a computer input device, and suggested he not be so upset. He could borrow one of ours until he could replace it. But no, I didn't understand, his 'mouse' had died. Being a bear of very little brain, it took me a while to make the leap to his rodent pet who had gone to the great beyond. So I learned to modify my communication to align with whomever I was interacting with. And checking if I understood what they were saying. Valuable lessons.

Jeroen was also good at teaching about boundaries. Personal boundaries. Sometimes, he simply couldn't deal with other people. Even if they were sitting next to him. And he would just withdraw and continue with whatever the activity was, taking no notice of whomever was beside him and whom he had been happily cooperating with only minutes before. It was pointless to try to break through. So you just learned to leave him to it. And on reflection, setting a boundary and not letting anyone break through it is a lesson that many of us can benefit from. And when you set the boundary and someone wants to break through it, you don't have to get upset, you just have to enforce it in a loving way. Nice lesson. Thanks Jeroen.

Although he did succeed in completing an MBO post-secondary education, it became apparent that Jeroen was never going to have a 'typical' employment profile. His physical condition wouldn't allow him to do a full week's work without fatigue. Which he could have responded to in any number of ways. The way he chose was to accept it, to learn to maneuver within the confines of the possible, and to take up a number of activities to give content and meaning to his life. He became a medieval role-player, with a specialization as a druid-like priest figure. He became a very proficient pastry chef, which considering that his diet when we first got to know him was restricted by his own choice to white bread and sugar, was one development of many that we just didn't see coming. And he learned everything he needed to know about the government support, financial and otherwise, for people with conditions of chronic disabilities.

These are all very valuable lessons, but that is not the most important lesson I learned from Jeroen.

Jeroen is 32 now. In all probability, he will not see 40.

He may not see 35.

His health has been dismally poor for a very long time.

He was still very young when doctors discovered that he was suffering from an incurable muscle degeneration disorder. Over time, they promised he would end up in a wheelchair. That promise was fulfilled. Upside? He can park anywhere he wants.

Then, some years later, he developed lung cancer. Doubly painful as he never smoked or consumed any strange chemicals as far as we know.

To be followed by a brain tumor. He went through the entire battery of treatments and the cancer went into remission, but the prognosis is still dismal

At the moment, Jeroen lives on his own, with a lot of support from the social services that are available to help people who need help at this level, in a small house in Zeeland, where he could afford to live in a style that he wanted to.

And he is in the process of dying. Slowly, but a lot faster than he would like, of course.

And this is where the biggest lesson that I learned from Jeroen comes in.

Jeroen is half my age this year. He knows he is dying. But he is not wallowing in it. He doesn't have the time. He's too busy working off his bucket list.

Now, what kind of bucket list can someone in his condition be working off, you might ask.

Well, he is currently the chairman of the Vereniging Vrije Spiritualiteit in Hoek, Zeeland.

He has worked at a hospice in Zeeland and at a pop podium in Terneuzen.

Well, a couple of months ago, he went gliding. As a passenger, of course, but still.

In a couple of weeks, he will be flying to Rome to board a cruise ship to take a two-week cruise of the Mediterranean Sea. Courtesy of an organization that helps people with serious mobility issues to undertake such activities and also with the active support of the cruise line personnel. And, on Tuesday, this week, Liesbeth's brother David, who is a licenced general aviation pilot, will be flying me down to Zeeland to pick Jeroen up for a flight around the countryside for a couple of hours.

Jeroen is dying. He knows he's dying. He has just decided not to let that interfere with his life more than absolutely necessary.

And that's the biggest lesson that I learned from Jeroen. Face it. We are all going to die. If Jeroen dies today, he will only have been half as old as I now am. But in the grand scheme of things, that 32 year difference is a rounding error. It won't even show up on the graph. So, in that knowledge, we are reminded of the words of Adelaide Crapsey, an American poet who also suffered greatly from chronic illness: "Why have I thought the dew Ephemeral when I Shall rest so short a time, myself, On earth?",

That knowledge, our ephemeral nature, can lead you to a conclusion of nihilism. Nothing matters. Why should I care? Why should I undertake anything? What's the point?

It can also lead you the other way: It is what it is. So I will fill my days with gladness and shout for joy and be happy all my days. If there is no meaning in the universe....no matter...I shall bring meaning.

You shouldn't think that I am ignoring the pain in life, and certainly the pain in the lives of people in Jeroen's condition. Muscular degeneration sucks. Constant fatigue sucks. Chemotherapy sucks. Radiation therapy sucks. And the pain that results from all of that sucks. And the frustration about not being able to do what you want and to achieve what you had aspired to sucks.

And having limited financial resources sucks. And being non-neural typical can suck. And having a spouse/partner/soul mate hurt you sucks. And not having a spouse/partner/soul mate can suck.

And no reasonable person would fault you for being depressed, and sad and listless in the face of it or simply if you get up and go gets up and goes.

But, with the example of Jeroen before me, that's not the choice I make.

I choose to deal with what is, as far as possible, and move forward.

So let the Ivy King win. I choose to hold high the banner of the Holly King, come what may.

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