

# CF, Medication, Sex and Love –

a man's perspective and a Little Confession

## 1. The Title; a Candid Talk

This talk seems to be about how medication, like in my case antibiotics and Kaftrio (also known as Trikafta\*), influenced my manhood. Actually, this is not true. It didn't. It influenced the sexual possibilities. Manhood is different from that.

For me, manhood doesn't exist, it's a concept, a figment of the mind. A series of unproven assumptions, distortions and caricatures. I wouldn't *know* what it is because – physically – I *am* (= appear to be) a so called man, and without having the opposite experience of womanhood, how would I define this correctly? It is just how it is. I could not add to or subtract from my manhood with any thought or belief. That would only be conceptual blahblah.

So, back to Sex and Love again, influenced by medication. This is not true either. Sorry for the confusing title. Love was never affected. It can't. Love is everything and it is beyond everything. This is true in a general sense, and it is true for the love that Debbie and I share especially. I wrote a Tale about that recently, about Love in three poems, you can read that [here](#). I put the word Love in the title to have a reason to explain this here. Love is so much more than sex or sexual possibilities. I will talk about that later – and then you will find out the second reason I put it in the title as well.

But don't worry, there is still a lot of medication and some sex in this talk – so that part of the title is correct. It's not a complete clickbait. There is something about sex that I think is worth mentioning in relation to medication and Cystic Fibrosis (CF).

It is not something you read about much on the internet. I think not even many doctors know about this. It might be sort of a taboo. So I think writing about it could fulfill a need (no pun intended). It will be a candid talk, because I think that when talking about this at all, one needs to be very clear and not beat around the bush. So there we go. If you don't like to read about genitals, sexual function and performance, by all means stop reading here. But I promise you, this is actually all about love and its many utterings, and nothing else. There is even another poem.

## 2. Kaftrio

Let me start with Kaftrio. Kaftrio is a medicine that is used as HEMT, highly effective modulator therapy. It is only used for treating people with CF, and only those among them with a specific gene-profile. About 90% of people with CF in the Netherlands are currently potentially eligible for Kaftrio. I am one of them.

### The first effects

When Kaftrio started with me, 5 months ago, I had some hopes. This type of medication has been around in the world for several years now, so some of the effects and side-effects are well known by now. Thus I expected to get a better lung function, some increase in weight, a reduction in inflammation and infection in the airways and a bit more energy. I truly needed this, after living with CF for 58 years my lung function was down to 25% (lucky enough not needing supplemental oxygen, yet), I was slightly underweight and not able to gain any pounds, on the contrary. I needed continuous antibiotic therapy and despite this, there was a chronic inflammation and infection going on in the airways which took a lot of my energy and well being. After my second anti-covid Moderna shot, my lungs deteriorated further suddenly, and I applied for compassionate use of Kaftrio, which was granted almost immediately. So, in August 2021, Kaftrio entered my body for the first time.

The effects were nothing less than spectacular. My lung function increased 15%, I gained 10 pounds in weight, inflammation and infection in the airways almost disappeared and all in all I gained, my estimate, about 50% energy. This all within one month. But there was more.

What I didn't expect is, that I also gained sexual energy. This was a bit naïve, in hindsight, because after all, healthy people tend to spend some of their overall energy on sexual activity, so if the overall level increases, sex is going to have its share of that too, wouldn't you say? And so it did. But Kaftrio had a more specific effect as well in the area. There was nothing about this in the information leaflet. I didn't read anything about it on the internet either. So, I started thinking about this, combining my experiences and knowledge.

### Kaftrio and the Balls

The *testes* (henceforth I will refer to them as "balls") are endocrine glands as well, like the pancreas, and their function is often impaired by CF because of the sticky fluids and mucus in the little canals inside. It is known by now, that the balls can be affected by the use of Kaftrio. Some men have reported a sort of inflammation, which resulted in painful balls for a while after starting Kaftrio. Fortunately, I didn't experience this.

What can also happen is, that the internal problems in the balls clear up more or less by using Kaftrio. Not that men suddenly become fertile again and could father children the normal way. The *vasa deferentia* (the little canals that transport the sperm from the by-balls – *epididymides* - to the prostate) are in most cases still either blocked or not developed in most men with CF. But there might be more activity in the balls due to Kaftrio nevertheless. Including more production of sperm and testosterone. I suspect, in my case this is what happened.

### Kaftrio and (sexual) energy

So, Kaftrio has definitely increased my overall energy and, more specific for this talk, my sexual energy as well. Both I attribute partly to a higher testosterone output caused by the balls functioning better. They are a bit larger as well now. And there are other factors, like the overall improved nutritional status, also because of Kaftrio and not using antibiotics continuously anymore. So my body is not permanently in crisis-mode. And there is more oxygen too and more energy. These will all contribute, and these are all consequences of taking Kaftrio.

### 3. Antibiotics; effects and side effects – CF is special

I mentioned antibiotics already a couple of times. I used a lot of those in my life. Already in my early youth, every cold needed a follow up by a course of antibiotics, because it would invariably turn into a bronchitis. From my 18<sup>th</sup> birthday on, I used (bacteriostatic; they slow down the growth of bacteria) antibiotics continuously, and even then I needed a course with heavy-duty antibiotics (bactericide; they kill bacteria) a couple of times per year to treat an exacerbation. To deal with or prevent pseudomonas infections I also used oral fluoroquinolones like Ciprofloxacin and, more recently, Levofloxacin. I needed these ever more (in higher doses) and ever more often when my lung function declined further. There was even a phase, about 7 years ago, where for 2 years I needed intravenous antibiotics that are normally only prescribed on the ICU, 6 times a year for 3 weeks in a row. These were Tazopip, Meropenem and Ceftazidime. Fortunately, these could be administered at home in my case.

They did the job of killing the bacteria and reducing inflammation very well, but after stopping the course, the infection and inflammation would return swiftly, so we had to alternate three different antibiotics to prevent resistance. Fortunately, after 15 or so of these courses (which I called chemo-therapy), the infections suddenly resided and I could go back to my normal scheme of truckloads of pills.

Antibiotics can have many side effects. Of course, in case of CF, there is no other way to go often, because the airway infection is life threatening soon, if not treated. And side effects have to be accepted. But knowing of the possible side effects nevertheless is helpful.

Most of the known side effects are based on normal use. Most patients take short courses of 7 to 10 days, in relatively low doses and the mentioned side effects are derived from that general use. In CF however, and in my case this was not different, patients are exposed to much higher levels of antibiotics. They take mostly twice or thrice the normal dose, the courses are often minimally three weeks, and they need not an occasional course, but many courses per year and often combined with continuous use of other antibiotics as well. And in many cases, they use antibiotics that are much more toxic than the normal stuff. People can get serious nerve damage from that.\*\*

#### Peripheral Neuropathy; Fluoroquinolones, a 2019-study

Well known is for instance the toxicity of some antibiotics (aminoglycosides like Tobramycin or Gentamycin) on the cranial nerves, specifically the hearing nerves, causing deafness in people with CF. And some reports also mention other nerve damage with some other antibiotics, but not much was certain about this or the underlying mechanism. Only in 2019 a very large study confirmed that for instance the use of fluoroquinolones was associated with a 47% increase in the occurrence of peripheral neuropathy, with a 3% increase for every day (!) of use. Especially, men and people over 60 years old are at risk. This concerns for instance antibiotics like Ciprofloxacin and Levofloxacin that are frequently used by people with CF to treat pseudomonas infections; also by me in long courses, in very high doses (the maximum allowed), and several times a year for more than 25 years. So for me, the causality in this case is beyond much doubt, even if the occurrence of this side effect is still rare in absolute terms.

And the absolute occurrence differs widely with circumstances and sex. For instance, you may (in the best case) need to treat about 1.5 million female patients with a 5 days course of these antibiotics to cause 1 case of peripheral neuropathy. That seems a rather insignificant risk. But if you treat male patients for 28 days, in the worst case only 22.000 patients are needed to cause an extra case of neuropathy. That is about 68 times more often. The number of patients needed to harm is inversely directly proportional with the duration of the treatment - and men are about 7 times more susceptible than women to neuropathic damage caused in this way. The research was based on standard dosing, but the risk might very well be dose-related. And it surely is frequency related. So I think in male people with CF, given the higher doses and more frequent and longer courses that they are exposed to, peripheral neuropathy may turn out to occur considerably more often than doctors or patients think, especially in elderly male patients.

#### Another approach to assess the risk; more research needed

In stead of this statistical approach, one can consider the phenomenal way: let me do some backwards engineering (this extrapolation from my personal situation is not scientific, but for me interesting all the same). In my case, being a male patient in the Netherlands, I am 1 of about 750 patients with CF. In my age group, I am even much more rare. Currently, there are only 130 people with CF in the Netherlands older than 50 years. About half of those are men, so I am one of a group of only 65. So, assuming that I represent my group faithfully, neuropathy may even occur in 1 in 65 cases of male older CF patients treated with fluoroquinolones.

Mind you, this is not a statistical chance, but an estimated rate of occurrence. But it is still rather significant I would say. If only 1 or 2 other males with CF in my age group in the Netherlands would suffer from the same problem, this would increase the occurrence to 1 in 32 or even 1 in 21. We don't know how many of those cases exist, but it would be very wise to do some research on that, I would think.

And if one already suffers from neuropathy, there is even more reason to be very careful with taking those antibiotics, and we should try to use as little as possible – few and shorter courses, in the lowest effective dose. But this is not what generally happens when these antibiotics are prescribed to CF patients. Doctors tend(ed) to prefer the highest allowed dose, prescribe when ever a culture of pseudomonas is present and seem to prefer long courses of 2-3 weeks, not considering the risk of peripheral neuropathy to be significant.

In general it is my experience as well that side-effects are more problematic with aging. Nowadays I am more prone to them than I was when I was younger. Probably this has to do with the clearing function of liver and kidneys - all organs of course work a bit less brilliant in older bodies.

#### My case; what and when

Well, in my case, some serious nerve damage happened indeed. It started slowly about 10 years ago, after many courses of ciprofloxacin, and the intravenous antibiotics seemed to have contributed to that considerably as well. Not in the ears, but in the extremities. It mostly influenced my hands and feet. There is a considerable diminishing of feeling and coordination. For instance, when I stumble, the reflexes in my legs are so slow, that I can't correct in time and find myself on the floor before my legs can compensate for a loss of balance. Running is

out of the question as well. Moreover, the feeling in my hands and fingers has changed, for which I had to adopt my way of playing the piano. This also happened in my legs and feet (not the piano playing, mind you), and there are also sensations like pain, tingling, numbing, burning, jabbing, and indifference to temperature. Especially at night this is sometimes a nuisance. Sometimes a little Tylenol helps, and I use a low dose of Diclofenac which also seems to suppress the symptoms and retard the progression. The Diclofenac had another positive effect on my airways by the way, diminishing the level of inflammation. This is how I got rid of the intravenous antibiotics 6 years ago.

Since taking Kaftrio, I hope this process of nerve damage will now stop or possibly even revert, because my need for antibiotics has drastically decreased. There is some hope that improvement indeed may occur, or have occurred already. Now we are coming to the sex-part again.

### Dimpotence<sup>©</sup>

The last couple of years, my penis too suffered a bit from this peripheral neuropathy, resulting in softer erections. This diminished potency (I would like to coin the word “Dimpotence” for this phenomenon; and the Dutch version “Dimpotentie”) is often caused by a deficient functioning in the nerves of the blood vessels and muscles that regulate the in- and outflow of blood on sexual arousing. It can also be a result of a diminished testosterone production. And a combination of those.

Fortunately, this did not influence the quality of our sexual life, because we never made a problem of that and there are a lot of ways to accommodate. Everyone can use his or her own fantasy to paint this picture, and so did we. There is no drama in that, it is only another possibility to be creative – and we love creativity, as you might have noticed on visiting our [website](#). We never considered using chemicals like Viagra by the way, it seemed not sufficiently important to do this. There are enough pills in my life as it is.

### Kaftrio to the Rescue! - Ringing the Door Bell

And recently the erection is definitely turning out a bit more jolly. It is still not at the level I remember from being 38 – nothing is, actually, not even my memory. So, I still can't ring the front door bell with it. But hey, I am 58 now so that figures. I will use the knockers. But it certainly improved. And as said, I fully attribute this to the use of Kaftrio, directly and indirectly. This is not an advert though. It might not work for every man this way. And it would be a pretty expensive aphrodisiac, so don't be silly.

But I thought I'd let you guys know anyway. Kaftrio can have unpleasant side effects, but this is definitely a bonus in our book. And now the evening pill of Kaftrio is blue, and indicated by the letter V. How funny is that?

## 4. Science is still behind

In case you go look for it, there is precious little scientific research about the influence of HEMT (Kaftrio/Trikafta) on the (fe)male reproductive system – so I will save you the effort. This is an area that is completely new and it still has to be developed.

The only article I could find (had to buy it fgs) is only a short communication that frankly, on reading, I found not worth the money I paid for\*\*\*. There are however a few pointers in it, also some references to hypogonadism (when the balls or ovaries produce too few sex hormones) which occurs frequently in people with CF. Also it contains some information on SRH (sexual reproductive health) in men, but it refers mostly to old research, which is both few in quantity and of course does not include the effect of HEMT.

## 5. Kaftrio, Energy and Sleeping

The extra energy also resulted in a different sleeping pattern by the way. I still fall asleep well, but often – which is new – awake rather quickly after a short while, and then I find myself unable to catch sleep again for some time. Occasionally for more than an hour. I have my little sleep- and activity tracker to back this up. Fortunately, I can always catch up by doing a siesta at daytime, so I don't mind being awake at night very much. I use it for meditating and every now and then I take a little stroll in the house, get cold and shivery, and then the bed feels very comfortable again which improves the chances of *Morpheus* and *Hypnos*, the gods of sleep, to visit me.

And fortunately, *Aphrodite*, *Cupid*, *Amor*, *Eros* and *Parvati* have never left us. We really treasure this and we are happy to accommodate and play with them as always.

## 6. Other Ways of Expressing (sexual) Energy

And so we are back to Love again. Of course, there are myriad ways to make love, having sex is only one of them. And one cannot convert these hormonal flares into having sex all the time. That would take the specialness out of the occasion - and there are so many fulfilling things to do, besides having sex. So, we always had other ways to express our passion as well. For instance by being tender with each other, dancing, laughing, playing, making a great meal for each other, or just being still and happy together. Or by painting or playing the piano, performing the more fierce compositions again, like Chopin's Polonaises – or the delicate and tender ones, like the Nocturnes.

Or ... by making poems! Swooned by devotion, the mind can be a beautiful servant in creating the most lovely things. One of these I present here, by way of a Little Confession of mine. You can also find it [here](#) on our website, projected on an enticing background.

But I will copy the plain text here as well, for it is sweet in its own right too:

## *Little Confession*

*I* wish your bijoux breasts I were  
So kept and so prochain  
So feeding and so feminine  
Now free, than cloaked again

*S*o slowly risen from the void  
Not knowing of their chances  
But getting ever more aware  
In easygoing dances

*W*ere I your bijoux breasts as well  
So soft, so cute, standfasting  
I would be sweet and unconcerned  
Immersed for everlasting

*M*y hands would them be holding  
And fingers would caress  
The lips would feel so tenderly  
And play them with finesse

*M*y kisses would be whirling  
And pressing all the time  
Around, on top and underneath  
The in-between sublime

*A*h, how would we be unified  
So everything, so cozy  
But wait, my love, now clear I see:  
We all along were wholly!

Of course, as you might have already guessed, this poem is dedicated to my lovely Debbie.  
I hope you enjoyed this Tale.  
I really did.

J.Paul Jordaans  
Grathem, the Netherlands,  
1 January 2022

P.S. The background you see to the poem on our website, is actually the very dress that Debbie wore on our wedding day in 2011. It still fits perfectly and she becomes more beautiful every day. It actually is not rosy, for Debbie is not green – in case you wondered. The original pre-photoshop colours can be seen [here](#), going with the original same poem in Dutch.

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*Foot notes and references*

\* Please **Vertex**, in future don't give your pills different names for different continents – there is only one Earth anyway, so why bother? It's so confusing and foolish.

\*\* **Association Between Peripheral Neuropathy and Exposure to Oral Fluoroquinolone or Amoxicillin-Clavulanate Therapy**; Daniel Morales, Alexandra Pacurariu, Jim Slattery et al, JAMA Neurol. 2019; 76(7):827-833.

(A very informative and free publication.)

\*\*\* **Men's health in the modern era of Cystic Fibrosis**; F.N. Kahn c.s., Journal of Cystic Fibrosis 20 (2021), p. 121-123.

(Please, Journal of Cystic Fibrosis/Elsevier, publish superficial findings like these for free, all be it only for the patients involved. I think the download price of \$34 is almost shameful.)