Don’t Whine

On tree wheels further

My Sepsis and beyond

Wilbert Kruijsen

Wilbert Kruijsen

Introduction

I offer you this booklet for free. In 2021, I suffered a sepsis with severe organ failure. With this book, I want to raise awareness and understanding among readers about the phenomenon of ‘sepsis’.
It is usually unknown, or described as blood poisoning. But it is unfortunately more than that, and education and research needs a lot of money.
Don’t Whine “ It has become a unique document in which Wilbert Kruijsen takes us on his patient journey. We see how the ‘struggle for life’ turns into the ‘struggle with life’. With a certain playfulness and at the same time very accurately, Kruijsen expresses how deeply sepsis and its consequences affect his life and that of his loved ones to the core.
Many a sepsis survivor will recognise it, that double of ‘being glad you survived’ but also ‘not recognising yourself again’, the ‘being allowed to move on’ but also the feeling of powerlessness: how am I going to do all this again?
In addition to the gratitude Wilbert feels for his survival, mourning in all its facets emerges: no longer being able to do what you could, no longer being who you were.
The latter is also an intense process for those close to him.’….

Idelette Nutma-Bade in the book's introduction.
Idelette is coordinator of ‘Sepsis and beyond’ and organises the annual Sepsis Lotgenoten Dag.

In August 2021, I am stricken with sepsis with severe organ failure. Blunt bad luck strikes me. The consequences are significant and not only for myself, but also for those around me, my wife, children and friends.

I change from a healthy 71-year-old man to an elderly man with all sorts of defects. With the help of many physiotherapists, a psychologist and others, I scramble up and regain my life.
Supported by my Mieke, children and grandchildren, who give me joy in life again with much encouragement.

Unfortunately, there are permanent limitations; I will have to learn to cope with this. I am a fighter and not someone who sits behind the geraniums. To the best of my ability, I have picked up my life again.

Don’t Whine will be my motto. No whining and if I can't get through life with two wheels, then let's get through life with three.

‘Every disadvantage has its advantage’

Willem van Hanegem

Don’t Whine, On three wheels further. My sepsis and beyond

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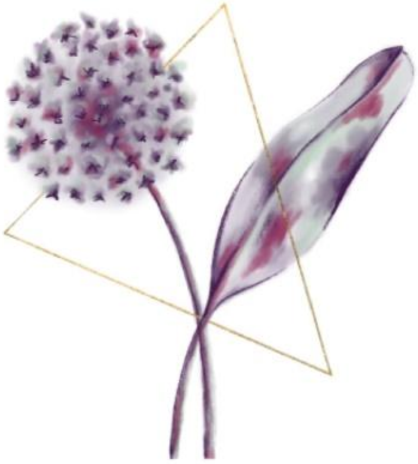
Foreword

In this book, I reflect on what happened to me and how, with the help of my wife Mieke, my children Niki, Gila and Jan and their loved ones, neighbours and friends, I scrambled back on my feet and picked up life as best I could. I had been messing around with my prostate for years. Lots of tests, punctures and the like. At night, I did have to go out often. In January 2021, I underwent surgery on my prostate. The operation went well. No nasty things were found. Fortunately, it was not cancer. Soon I start having trouble again, no pain, but have to go out twice at night. Later, I hear that at my age, it is fairly normal. If only I had known that.
The title of this book *Don't Whine* comes from the Nijmegen dialect. It means something like 'don't nag'. On Wikipedia, we find the following: 'Nijmeegs (proper name Nimwaegs or Nimweegs) is the urban dialect of the Nijmegen working class'. An appendix contains a detailed explanation.

Word of thanks
Thanks to Mieke, my supporter and wife, and thanks to Frans Wildenborg for their valuable comments on earlier versions of this volume.
Thanks are certainly due to Idelette Nutma-Bade, to friend and photographer Matthé Dalderup for the photos on the front and back cover. Thanks also to Frank van Osch, documentary filmmaker and singer-songwriter for his inspiring booklet.
Without support and inspiration from them and other friends, writing and publishing this booklet would have been a lot more difficult.

Wilbert Kruijsen, December 2024

CONTENTS



The triangle represents the connection, between body, mind and our brain. But also for the connection between all systems and how a sepsis can mess up all those systems considerably.

The dandelion symbolises a growth process, where you eventually escape from the framework of what happened to you and start a new part of your life. (drawing by Nina de Laat)

Introduction

'Don't Whine' offers a very personal, but also educational insight into the life of Wilbert Kruijsen after his overwhelming sepsis; it connects his very poignantly described experience with the actual impact of this serious illness.
It has become a unique document in which Wilbert Kruijsen takes us on his patient journey. We see how the 'struggle for life' turns into the 'struggle with life'. With a certain playfulness and at the same time very accurately, Kruijsen expresses how deeply sepsis and its consequences affect his life and that of his loved ones to the core.
Many sepsis survivors will recognise it, that double of 'being glad you survived' but also 'not recognising yourself again', the 'being allowed to move on' but also the feeling of powerlessness: how am I going to do all this again? In addition to the gratitude Wilbert feels for his survival, mourning in all its facets emerges: no longer being able to do what you could, no longer being who you were. The latter is also an intense process for those closest to him.
In doing so, Wilbert shows, among other things, how the effects of sepsis are largely invisible at first sight. Apart from shaky walking and proceeding on 'three wheels', much is hidden from the eye of the outside world.

But inside, especially in the brain, there is all the more going on: rapid overstimulation, difficulty with memory, concentration and information processing, emotional lability et cetera constitute 'hidden limitations'.
Life is changed because of it, and this book lays everything open on the table: the capriciousness of recovery, and life that often feels like a task, with a body that does not cooperate.
But Wilbert also shows how he manages to tap into qualities in himself again and that he knows how to enjoy himself again, together with his loved ones.

Sepsis, the syndrome that is an enormous 'hold-up' on your health and life, the syndrome that affects 60,000 people a year in the Netherlands and saddles 75% of 'survivors' with new symptoms, puts life on hold, but did not silence Wilbert, on the contrary …
In this way, Wilbert is making a special contribution to creating more awareness around sepsis. And instead of throwing in the towel, he used his experiences in a positive way: 'Don't Whine'.
It has become a beautiful and inspiring book, illustrated with impressive photos that show vulnerability and strength, and will not leave the reader unmoved.

Idelette Nutma
Experiential guidance, counselling and education. 'For greater understanding and better recovery '
https://www.sepsis-en-daarna.nl

For the Nijmegen Roman mask in cycling clothes, a year before my sepsis.

What happened

A man of then 71, I undergo prostate surgery with the green-laser technique at the end of January 2021. I have had symptoms of my prostate for years by then.
To resolve them for good, well 10 years is given to me, I undergo surgery: the size of my prostate will be reduced by 70%. Fortunately, no other nasties are found.
After a day at the academic hospital Radboudumc, I am discharged. I go home to regain my strength.
Because after a few months the urinary symptoms do return, I visit the urology outpatient clinic again for a check-up at the end of August.
Although I am on time, after waiting an hour for the urologist, I am helped by a nurse who is not actually on duty. By her own admission, she has 27 years of experience. So she does the examination, a peek inside the bladder. For men my age, an all too familiar hassle.
Trousers off, and there I sit on a kind of delivery chair, legs wide. She inserts a scope into my pee-pee, which makes its way to my bladder.

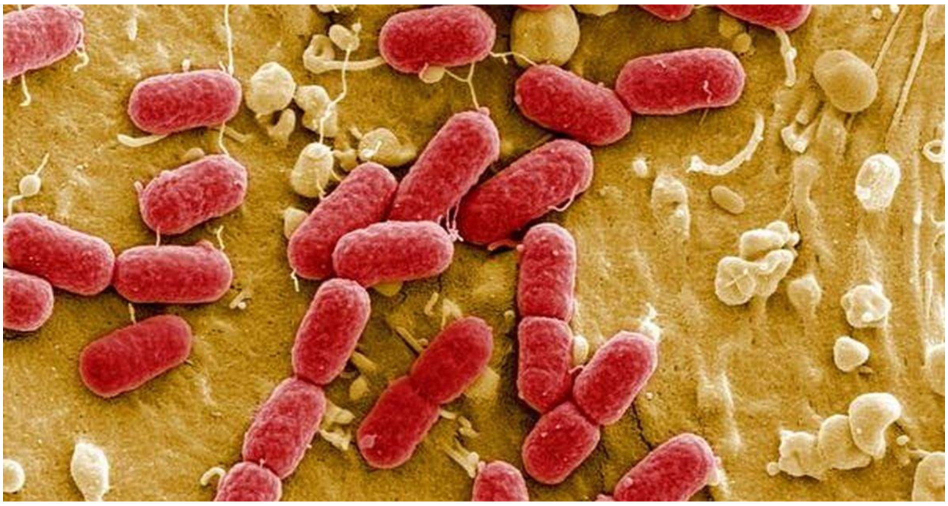
With some pain, that scope reaches my bladder, she looks at the screen and sees that there is nothing special.
After the treatment, I return to Malden. The pain is severe and persists. On Mieke's advice, I go to the GP and come home with antibiotic pills. But the pain gets worse. I get feverish and at night I go downstairs because I feel bad. Later at night, I call Mieke at the bottom of the stairs. The temperature is over 40 degrees. Ouch. Then the lights literally go out on me. Something is very wrong. After that, I can't remember anything.

Mieke calls 112, the ambulance arrives in 10 minutes. The paramedics see immediately that something is very wrong. An infusion is immediately inserted and, with the siren blaring, we are taken to the Radboudumc in Nijmegen.

At the Radboud's emergency room (SEH), all stops are pulled out. I am immediately driven to the ICU and hooked up to various machines, IVs are inserted and tests are started.

Quickly, the doctors conclude that I have suffered septic shock with severe organ failure. My heart and lungs are still functioning well. However, my liver, kidneys and intestines have suffered severe damage. A bacterium, E. coli bacteria, entered my bloodstream.

Although E. coli (Escherichia coli) does not cause disease in humans under normal circumstances, it is the most common pathogen of urinary tract infections. Certain variants can also cause gastrointestinal infections, sometimes with serious additional symptoms of illness. Escherichia coli is related to the Enterobacteriaceae and can cause infections both inside and outside the intestine. The main pathogen of infections in the gut is enterohaemorrhagic E. coli (EHEC or Enterohemorrhagic Escherichia coli). This is a shiga-toxin-producing E. coli (STEC or Shiga-toxin-producing E. coli strains) that causes severe intestinal infection. The incidence is generally low, but the risk lies mainly in the outbreak potential due to contaminated water and/or food. Especially in people with reduced immunity, E. colicauses infections outside the intestine, including bloodstream infections. (Source: RIVM, website 2024)

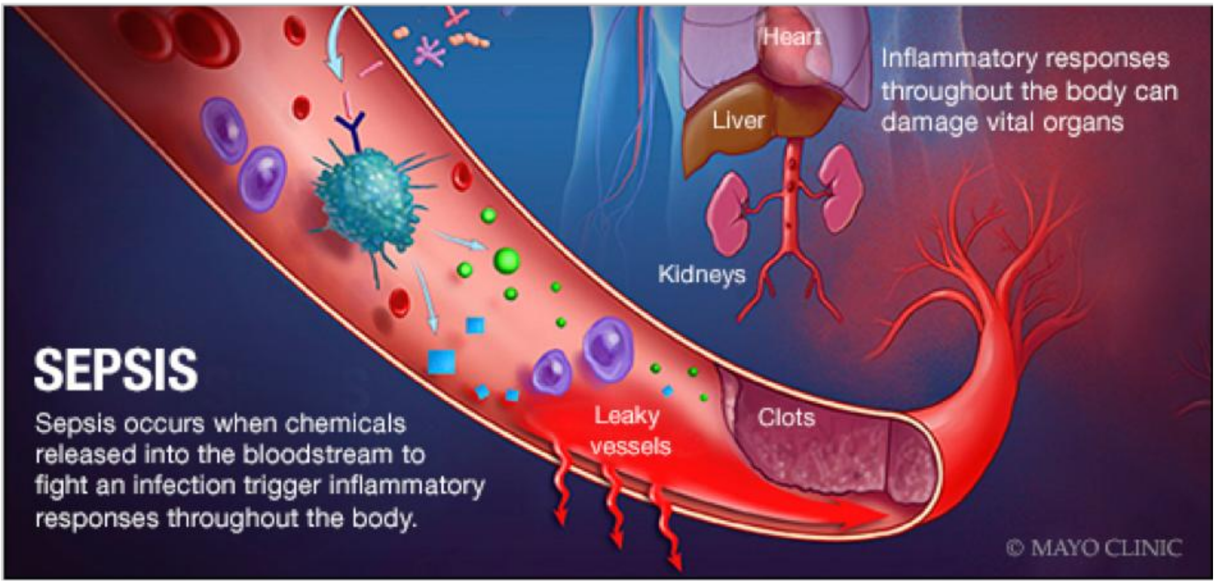


I survived, because I:
- got to the Radboudumc quickly from Malden, and
- get fantastic doctors and nurses at the bedside, people with knowledge, people who know about what sepsis is.

But even more factors have been decisive.
'Thanks to your parents ' *genes* AND a *good condition*, you survived, ' are the words of the ICU head.
Yes, I survived, also thanks to the quick admission, my good condition and definitely thanks to my parents' genes. I crawled through the eye of the needle. A year later, I visited my room in the ICU and also the family room (*nerve room,* according to Jan) under the guidance of an ICU doctor. It didn't do much for me.
Many people have heard of blood poisoning, but they have never heard of sepsis. It is not widely known.
Although many people contract sepsis in the Netherlands and more than 10,000 people die from it every year, this occurrence is unfortunately overshadowed by other diseases or ignorance. Ten thousand may not be a large number, but the consequences are huge: it is the fourth deadliest disease in the Netherlands. And if you survive it, you usually suffer damage to body and mind.

In Africa, where generally health care is sadly inferior, more than 10 million people a year die of sepsis.

If you drop the term sepsis in the Netherlands, most people don't know what it is. Now, I do often hear from acquaintances that they have had sepsis once.



For example, a former classmate recently told me that he developed sepsis 20 years ago because he had pulled off a piece of his toenail by hand, until it bled. As a result, a bacterium had entered his bloodstream resulting in sepsis. He was in a coma for 10 days and followed a long recovery process.

My dentist spontaneously mentioned that when I was at the practice for treatment, she once had sepsis. Sepsis can occur precisely when a tooth is extracted. The mouth is a source of bacteria. Therefore, antibiotics are often prescribed by the dentist when a tooth is extracted.

So it is more common than people realise. The phenomenon is well known in the medical world, but unfortunately not yet to the common ‘man’. In some cases it is preventable, but it is not always recognised.

My liver has fortunately recovered well over the years. My kidneys have been under the control of the nephrologist for 3 years. Every six months I went to the Radboudumc where blood and other tests took place. Each time with a positive result. I was discharged from there in April 2024 and the GP now gets the six-monthly check-up under his care.

At one moment I did not succeed anymore to describe my experiences. I could not, too short? Too close? Just wait, people say. It is too early perhaps, never mind. Be glad you are alive, others say.

But still, I want to describe it.

Then I stop writing for a while and often talk to others about it. Not only I want to get it off my chest, but with this story I also want to raise awareness of sepsis.

To get out of the writing impasse, I get the tip to look for a bread writer.

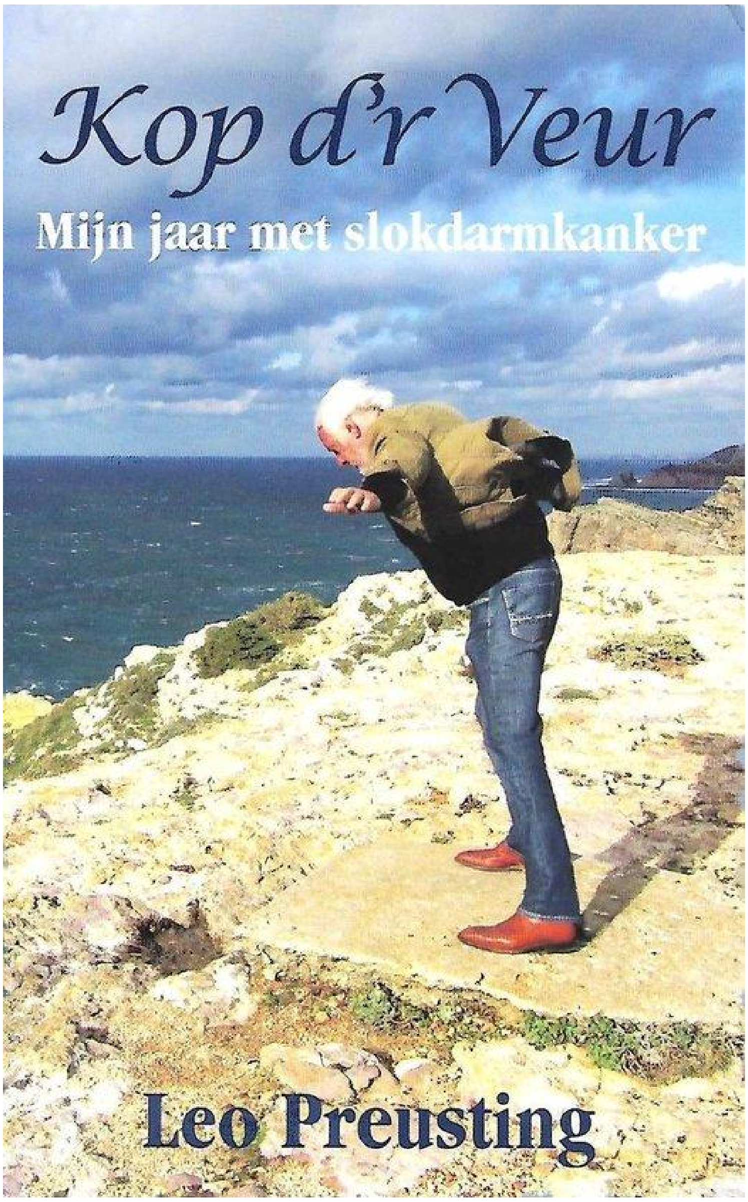
I approach local press with an e-mail. Not once, but twice, politely asking if there might be an editor within their ranks who could help me.

I get no response to these emails. Apparently, they are too busy spreading local news about accidents and calamities and the like. Through the medium of ‘LinkedIn’, I try again. Everyone I approach is too busy. With what? Everyone must have a reason, or does not see the seriousness of sepsis.

Having processed this disappointment to some extent, I pull myself together.

There will and must be a book on sepsis. That's how persistent I am. Especially after visiting Leo Preusting, who tells me the story of the oesophageal cancer he survived.

I read his book titled Kop d'r Veur. My year with oesophageal cancer. This gives me extra motivation to keep going and not stop writing down my story.



Fragments from 9 days of coma

Let me use Mieke's words to describe what the first days of my sepsis were like. Of those first nine days, I cannot remember anything myself of course ... a black hole.
Mieke keeps a diary of my time in the ICU. This is recommended by the Radboudumc, Intensive Care and Medium Care. Below are some excerpts.

Saturday 28 August 2021, coma day 1

On the night of 27-28 August, Wb (Wilbert) becomes very ill with a high fever. He shakes and shakes a lot. I call 112 who refer me to the GP clinic. I have to come with Wb. I can't. He then suddenly falls away and is unconscious. Called 112 again. Ambulance is there in 15 minutes. And with siren to the Radboud Emergency Department. Time: 06:15. There he is treated by many staff with IVs, blood pressure medicine, etc. ICU staff come to take over after an hour. A nurse tells me he is really very sick.

Wb is intubated, on a ventilator. They took a lot of time to stabilise him. Niki and Jesse come to the ICU. They are nearby. We wait in the family room (also called 'nerve room' by our Jan) for a long time for a doctor to give us clearly explaining what happened and what they plan to do in terms of treatment.

Bladder infection -> infection -> bacteria in the blood -> sepsis = blood poisoning.

Very dangerous. Very low blood pressure, very high fever.

Beknopte informatie en dagboek

Intensive Care en Medium Care

Radboudumc

10.00 am. Jan also comes. 1 p.m. Gila too. Charlotte too. Niki and Jesse go for a walk with Teun. Jan Hee is in the Ardennes.

The children immediately cancelled their appointments.

4pm me home in Malden, had dinner together. Niki cooked.

19.00 called to ICU.

7.30pm. Still went to Wb, is calm, fever dropped, blood pressure medicine reduced. 8.35pm home.

Sunday 29 August

10.00 Jan and Mieke at Wb. Fever reduced. Antibiotic is catching on. He does have respiratory support.

Monday 30 August

6.00 called to Radboud. Wb is not awake. There is a CT scan of the abdomen. Intestines are not working (well). Heart is good, kidney function poor. Liver function not good, coagulation not good.

Tuesday 31 August

10am Mieke at Wb. Jan is in the family room working. The nurse brings Jan in.

3pm. Family discussion with Dr Bernard Fikkers. He speaks for the first time about possible damage to the brain. EMG (An EMG measures muscle response to electrical activity and how much electrical activity a muscle contraction produces). Score was 3, should be 15.

This scares us a lot. But nothing is certain, a lot of uncertainty at the moment.

Wednesday 1 September

11.15 Mieke at WB. Neurologist comes and does some tests to see how deep he is still asleep. He is not responding at all.

They will consult with the IC doctor. Possibly a CT scan of the brain. A lot of uncertainty still unfortunately. We are very worried.

Thursday 2 September

10am. Niki and Mieke to Wb. Jesse is in the family room working. Physio met; doing arm and leg exercises with him. Some more muscle tension now.

12.00 pm. Physician and nurse at bedside. MDL doctor attaches probe tube to intestines for feeding.

3.30pm. Mieke back with Niki. News read out, including football. Also Strava news, music on. Hands and feet massaged. Then Wb started trembling, shivering a lot. Cold, sign of life? Fever? Blood pressure very high: 178-190.

Friday 3 September

10am. Jan and Mieke at Wb. Doctor B. Fikkers with co. visiting. Wb: coughing and frowning. Liver values are good except for bilirubin. Kidneys on dialysis still, do stop once. Bowel and stomach are good. He needs to wake up now. An MRI after the weekend if he hasn't woken up yet.

He is still shivering erratically from fever.

7pm. Jan and Charlotte come to visit. 37.3 degrees fever. Frown 2 times. Mieke at Niki's for dinner and walked from 6pm to 9pm.

Saturday, September 4

Niki visiting at 10am along with Jesse until about 1pm. Few changes, quiet night. Liver values slightly better. Night shift noticed Wb opening his eyes briefly. Occasional grimace and reflex with open mouth. Dialysis off for a while. Niki and Jesse read a few articles from the UK. And 2 little birds 'flew in'. Music by Rammstein put on.

Mieke eats at Jesse and Niki's place, along with Gila.

Sunday 5 September

Ellen, the ICU doctor noticed that WB opens his eyes and sometimes frowns. Jan and Mieke also see it, twice.

Jan asked: do you hear us, nod your eyes and he did!!! He doesn't see you but probably Wb hears us.

Eyes open again, frowning and coughing. It does take a lot of effort on his part, according to us. Arms, hands and legs are not responding yet.

Good start to a beautiful Sunday. Birds watch over him.

15.00: Mieke notes that Wb opens eyes more often; Did not move.

7pm. Jan and Charlotte: pupils moved!!! Otherwise stable, result of MRI they don't know yet. Mieke had dinner with Gerrit and Marleen.

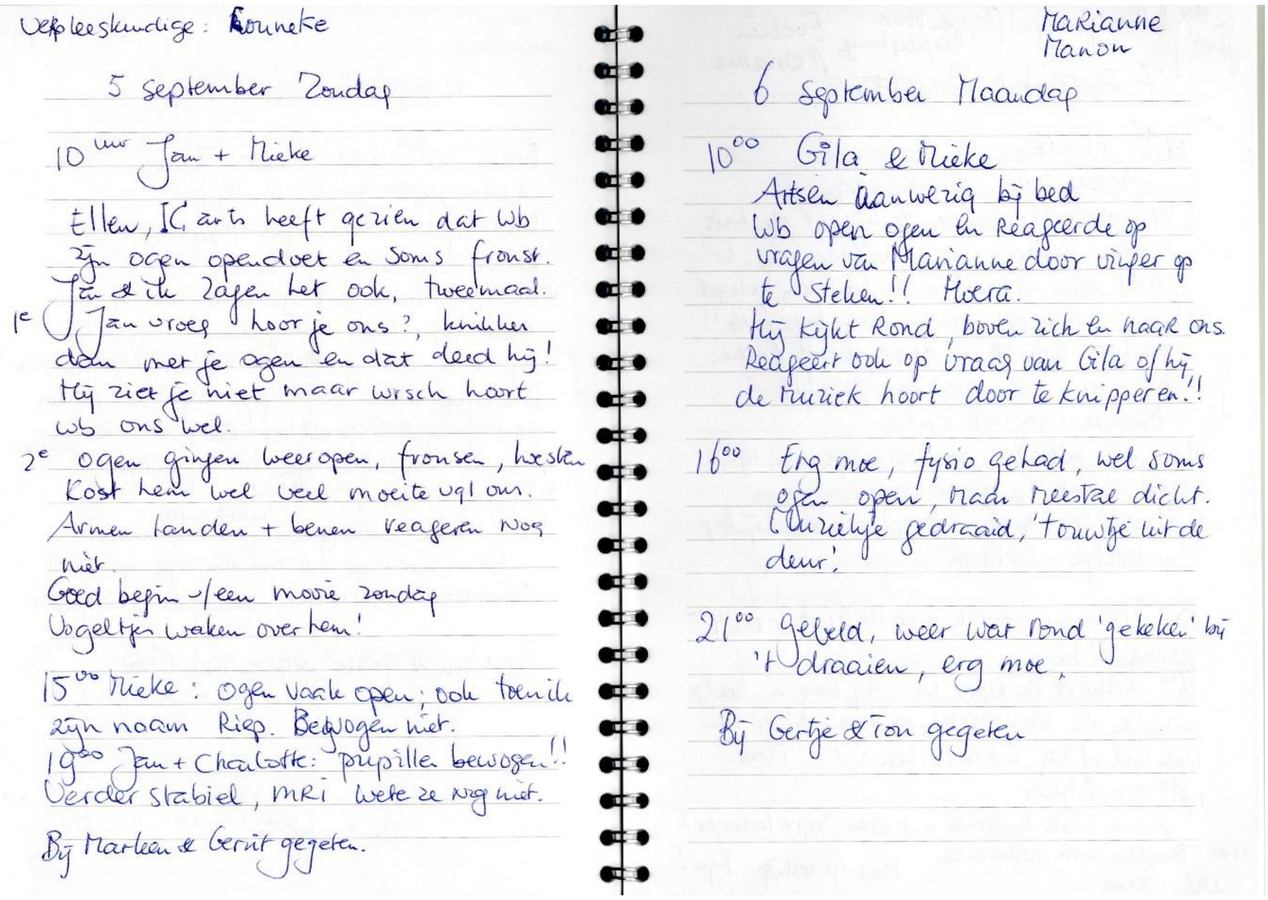
Monday 6 September

10.00am: Gila and Mieke visiting Wb. Doctors present at Wb's bedside. He lies with eyes open and responds to nurse Marianne's questions by raising finger. Hooray!

He looks around, above himself and at us. Also responds to Gila's question about whether he hears the music by blinking. 4pm. Very tired, had physio, eyes open sometimes but mostly closed. Music played 'the string from the door'. 9pm, called, looked around again at turning, very tired.

Last night they had to take the line out of the neck, blocked (I thought). A new line was inserted in the groin. Wb looks up when I greet him!!! He has also already squeezed the hand of Evelien, the nurse. They are quite positive. Kidney dialysis is still needed, though.

Wb is exhausted, but still opens his eyes a few times. Hair washed, shaved and he lies upright a bit. 15.00: Family discussion with Dr Groot and four of us. 16.00: Niki and I to WB. He is a bit awake and immediately looks up at Niki and looks like he wants to smile. Nice. 5.30pm. Home. Lies and Niek arrive with food, soup and lasagne. Jan, Charlotte, Niki and I join them. Very cosy. Outside, it is very warm: 28 degrees.



Verpleeskundige: Ronneke

5 september Zondag

10^{uur} Jan + Mieke

Ellen, IC arts heeft gezien dat Wb
zijn ogen opendoet en soms fronst.
Jan & ik zagen het ook, tweemaal.
1e Jan vroeg hoor je ons?, knipper
dan met je ogen en dat deed hij!
Hij ziet je niet maar wrsch hoort
Wb ons wel.
2e ogen gingen weer open, fronsen, hoesten
Kost hem wel veel moeite vgl ons.
Armen handen + benen reageren nog
niet.
Goed begin v/een mooie zondag
Vogeltjes waken over hem!

15^{00} Mieke: ogen vaak open; ook toen ik
zijn naam riep. Bewogen niet.
19^{00} Jan + Charlotte: pupillen bewogen!!
Verder stabiel, MRI weten ze nog niet.

Bij Marleen & Gerrit gegeten.

Marianne
Manon

6 September Maandag

10^{00} Gila & Mieke
Artsen aanwezig bij bed
Wb open ogen en reageerde op
vragen van Marianne door vinger op
te steken!! Hoera.
Hij kijkt rond, boven zich en naar ons.
Reageert ook op vraag van Gila of hij
de muziek hoort door te knipperen!!

16^{00} Erg moe, fysio gehad, wel soms
ogen open, maar meestal dicht.
'Muziekje gedraaid, 'touwtje uit de
deur'.

21^{00} Gebeld, weer wat rond 'gekeken' bij
't draaien, erg moe.

Bij Gertje & Ton gegeten

Wednesday, 8 September

10am Gila visiting Wb. Physio was there. Put Wb on the edge of the bed between pillows. Went well. Sat like that for quarter of an hour. Nice!!! He is already a bit more awake and looking around a lot. Reacts a bit more alert. Kidneys still on dialysis. Physio comes every day now.

3pm. Wb is cycling on a kind of bed bike. Like an e-bike he is supported. Going well, about 30 minutes. Also sat on the bed edge again. Did some reading aloud.

Thursday 9 September

9.45 Mieke back at Wb, Jan arrives a bit later. Test done to see if ventilation could stop completely. That went well. Coughing a lot but that's just as well.

His eyes look alert, but also tired quickly. Had lunch with Jan in Valdin.

3pm. Brigit, the nurse, calls to say the tube is out and Wb can talk, laboriously and difficult to understand. Great news. Straight to it, he sometimes answers your questions well but is also very confused. Did some reading to him. Jan mentions his name a few times, talks to Wb about wine and Portugal. Sharp sometimes, confused sometimes.

After 9 days of floating between heaven and earth, I wake up and am taken to Medium Care.

A preliminary conclusion is: a Septic Shock (urosepsis) with severe organ failure: my kidneys are functioning at only 14% and my liver and intestines have suffered considerable damage.

Again: a favourable galaxy, good fitness (no alcohol, no smoking and up to 300 km weekly on the road bike) AND apparently good genes from my parents saved me.

Friday 10 September

10am. Mieke at Wb's place. Doctors present, tube feeding ended, doctor gives Wb custard and then gives the tray to me to give it to him. 10 bites given. IC doctor asks if he likes it. Wb says after thinking for a moment: that's enough.

Then read some aloud and gave some custard again. Physio helped him sit on the edge of the bed. Placed pillows in his back. He holds his head upright quite well. She also does some breathing exercises, went reasonably well.

Talking is slow and sometimes not understandable, but often. Wb is also confused. If continuous dialysis can be terminated, he can go to Medium Care. Nephrologist has yet to decide. Speech therapist also coming.

16:30. Niki comes to visit. Still tube feeding, he ate too little, very tired and sleeps a lot.

After the weekend to Medium Care and dialysis for kidney disease a few times a week.

Saturday 11 September

9.45 am. Visit Mieke to Wb. Had a quiet night. He asked for his glasses and he has them on now. He smiles when I come in, and says hello poo. Then falls asleep for a while. Asks for Teun and cries. Showed calendar with pictures. Activate brain? Wb talks a lot, sometimes unintelligibly, 'I want cake'.

Sitting on bed edge with water ice cream, 3 licks, 2 bites, then enough. He has hip pain when sitting down. According to the doctor, it comes from lying down. Talks a lot, also crazy things, confused too. Reading from the whiteboard went well.

16.00 Gila visited. Wb quickly emotional, talks a lot about poop and farts, haha. About Obama and Taliban, about him getting sick so fast and money. Wb says to Gila 'I want some goodies'.

Dialysis machine off, keeps malfunctioning, disconnected. They will monitor the values and depending on that they will reconnect the honking machine.

Sunday 12 September

10am. Niki present. Wb asleep, later clear again. He is already talking better. He considers himself an old prick. Not going to the MC now due to confusion. Lonneke, the nurse, found him a bit more confused. He had seen people in the room last night. Sat on the bed edge again. Dialysis reconnected, values were down. He likes Teun to come. Anaemia, HB is only 4.5. Yesterday it was 5.1. Niki found him no more confused than yesterday. He has hip pain.

16.00 Gila, Teun and Jan in the background, visiting. Very tired. Very nice that Teun was there. Going to MC tomorrow and dialysis three times if not weak. Wb gets medication for confusion. Waste products and this medication make him tired quickly.

Monday, 13 September

Wb is drowsy and does not say much; he is given blood added. At 2pm, Wb is taken to the Medium Care (MC) ward. It is a nice ward; immediately the physio is present, WB has to sit on the bed edge. After that, he sleeps immediately.

Tuesday, 14 September

Mieke comes to visit. Wb is nicely dressed, in bed, awake and looking outside. Music no, reading to him no. Dialysis nurse comes, machine connected, fails, lines are flushed. At 2pm a family meeting. Wb goes to Urology department. We worried. Liver is good, but kidney function still not good. Who is monitoring the neurological aspect? Is our question. Doctor thinks Wb is well enough for a regular ward.

Wednesday, 15 September

At 10.30 am, Mieke is present, WB is asleep and tired. Logotherapist feeds WB with a teaspoon of water, which goes well. It takes WB a lot of effort to sit on the edge of the bed. To kidney dialysis at 14.00, not back until 19.15! WB gets only water and tube feedings. He asks 'what is wrong with me anyway?'

Thursday, 16 September

Wb sat on the bed edge, I read to him a bit; physio and speech therapy arrive. In the afternoon, Niki visits. She decorated the room and cut Wb's nails; he is very talkative.

Friday, 17 September

Wb tries out his mobile but cannot operate it himself and that makes him very angry. I read him a story. Wb stands by the bed for a while with the help of the physio. He had a restless night, pulled out the tube feeding, he sees ghosts. On dialysis again.

Saturday 18 September

With Wolfgang and Jan briefly video calling.

Sunday 19 September

Visit from the doctors. They are very worried about his kidneys. Rehabilitation really needs to get going now. A family meeting is arranged with the nephrologist and rehabilitation doctor. Wb has showered, lies on bed panting from exertion. Talks a lot and just gives orders.

Mieke comes to say goodnight to him at 8pm. Wb sat in the armchair and ‘cruised’ down the corridor (his words).

Monday, 20 September

12am Wb off to dialysis again. Gila is there, he is very restless. After dialysis, he did wait 1.5 hours for transport back. Nephrologist still visits, has slightly more positive news.

Tuesday 21 September

Jan, Gila and Teun are with Wb, grandpa. Wb is very happy to see Teun. Intensive rehabilitation is unfortunately not yet possible because Wb has to go to kidney dialysis very often.

Wednesday, 22 September

He is very restless at night and then he keeps calling the nurse. A music from spotify calms him down a bit. Nursing has asked if family can come and sleep with him. Jan sleeps with Wb, which reassures him.

Gila at Wb. On dialysis, he has a lot of headache and vomited during transport back. Wb receives blood infusion.

23 September to discharge on 14 October

Things continue to go up and down with Wb. He suffers a lot of delirium. At night, neighbours, friends and children take turns staying with Wb. He cannot and does not want to sleep alone. According to him, Mieke should be spared.

‘with Niki in front of the entrance to the Radboud,

sniffing fresh air. He liked it very much.'

The dialysis is a terrible affair every time and takes a very long time, up to 4 hours and taking me there and back an hour too, if they haven't forgotten to arrange transport. Because of the agitation, I am given the drug haldol for a while. Fortunately, I no longer see ghosts from then on.

Slowly but surely, sleeping also improves, especially because someone keeps sleeping over. On 1 October the liberating news arrives that the kidney dialysis lines can be removed and the dialysis can be stopped. Recovery continues, on 6 October I eat by myself again and departure for a rehabilitation centre is scheduled. Klimmendaal in Arnhem has been chosen for rehabilitation.

The urologist also walked in a few times. He was quite taken aback; he had never experienced this before. I told him I was ‘excusing’ him from the event.

My days in the Raboudumc don't look very exciting otherwise, from blood tests to kidney dialysis. Via spotify, I listen to a lot of music, a lot of old blues. Niki even arranges a subscription for me so I am not bothered by the annoying commercials in between.

Klimmendaal

Finally, on 14 October, I am discharged from the Radboudumc and transported by ambulance to the rehabilitation centre Klimmendaal in Arnhem.

The corona epidemic passes me by completely at first. Once at Klimmendaal, things are briefly tenuous when a room next to me is prepared for a corona patient. Everything is shielded with plastic, I am no longer allowed in my wheelchair in the corridor. Who puts a corona patient among rehabilitating people? Apparently the need is very high. In the end, no corona patient comes and everything goes back to ‘normal’.

REHABILITATION

After a period of about 2 months in hospital (ICU, Medium Care and Urology department), I am discharged from the Radboudumc. Although my kidney function is very low and the tube feeding has just ended, I am allowed to start rehabilitation at the Klimmendaal rehabilitation centre near Arnhem. Far away from the outside world, hidden in the woods outside Arnhem, and near the former Mies Bouwman's Het Dorp.

I don not know a rehabilitation centre by heart, fortunately because you should not go there too often. With the word rehabilitation, there is hope for recovery, hope for a life. The nurses here are different from those in a hospital. Decisive, very clear and less caring. That takes a lot of getting used to because in the Radboud I was used to everything being handed to me. Now I have to do everything, well, myself. And that is not easy.

I really have to get used to eating. I am used to tube feeding, a life-saving stuff, but it is not very tasty, even very dirty.

For as much as a year afterwards, I have had no appetite or taste at home; I eat because I want to survive. Everything I am served at Klimmendaal and at home has no taste. I eat it because otherwise I will die. The only things I like are sweet things.

After a week of getting used to Klimmendaal, *'we are here to rehabilitate, and so pyjamas off'*, and little to no ability to eat, I start eating a little again.

My sister Liesbeth found a remedy through an old Chinese acupuncturist: eat drawn, fresh chicken soup. Clear soup at first and a few days later some chicken meat and vegetables in it. I still have great difficulty swallowing, and I often choke.

After a week, at the insistence of my sister and the nursing staff, I eat something again, although in my mind I had already ordered the coffin. I need to gain weight again, as I have lost 15 kg. I weigh only 79 kg at that point.

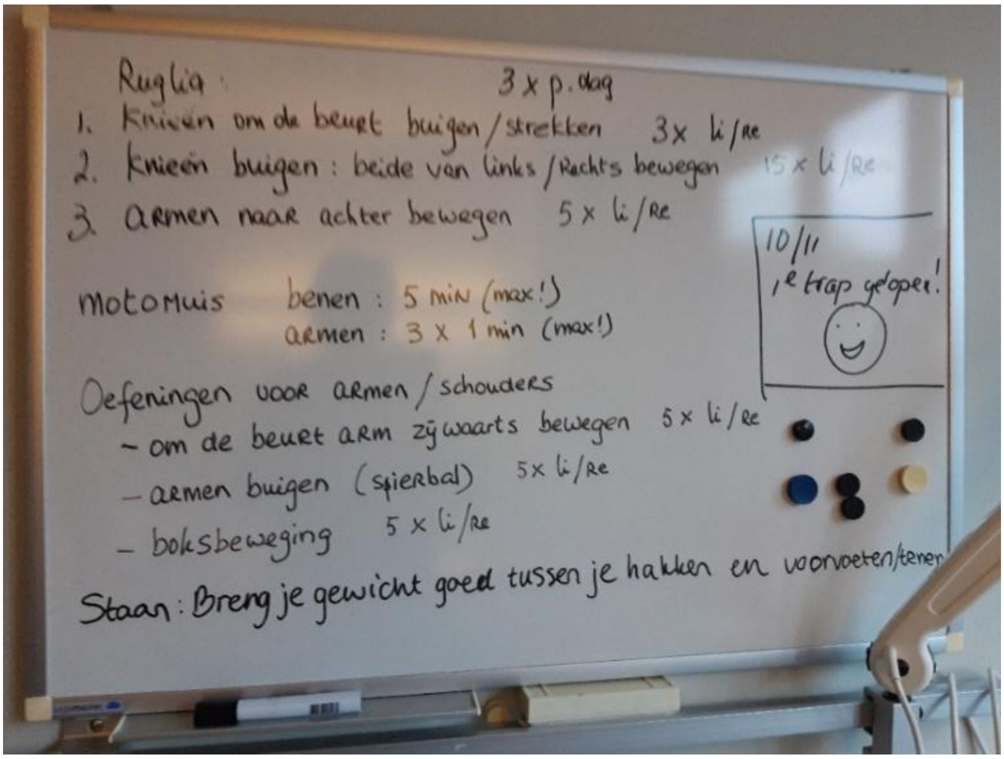
At one of the many check-ups in the Radboudumc, I get the good news that my kidney function has risen to 36% again. Even better news I am told is that my daughter Niki is pregnant.

In the nearly two months I spend in Klimmendaal, I follow an intensive programme with occupational therapists, physiotherapists, doctors, a social worker and a psychologist. Every week I spend hours in the gym and the occupational therapists play a game of badminton with me, or we try to craft some things. But it is struggling. I keep my spirits up.

I get many visits from friends and loved ones. My daughter Gila with her son Teun can also be found at my sickbed, as evidenced by the picture on the next page.

Many friends and family members are very involved and visit often, such as Henk Horstink and my sister Bernadette.

I do my exercises every day in the Kimmendaal gym to regain strength. It is not easy, but I exercise more than I am told to. After all, I want to go home.



Ruglig : 3 x p. dag

1. Knieën om de beurt buigen / strekken 3x li/Re
2. knieën buigen : beide van links / Rechts bewegen 15 x li/Re
3. armen naar achter bewegen 5 x li/Re

motomuis benen : 5 min (max!)
armen : 3 x 1 min (max!)

Oefeningen voor armen / schouders
- om de beurt arm zijwaarts bewegen 5 x li/Re
- armen buigen (spierbal) 5x li/Re
- boksbeweging 5 x li/Re

Staan: Breng je gewicht goed tussen je hakken en voorvoeten/tenen

10/11
1e trap gelopen!

Exercises and more exercises every day. My muscles need to strengthen and get going again after the long lie-in. Grandson Teun enjoys playing with the wooden dog I made for him in better times.

I get socks as a present from my dear sister Liesbeth with the letter **V** on them . Socks that I put on when I can go home again. For me, the **V** stands for Victory. It really feels like a victory when I put them on for the first time.

On the last day, it is still corona time, the staff at Klimmendaal wave me off. In their office hangs my photo, which I donated to them as a thank you for their good care.

After 2 months of intensive training with physio and occupational therapy, talks with social work and the psychologist there and 15 kilos lighter, I belong to the realm of the living again.

I PICK UP LIFE AGAIN

On 8 December 2021, I am discharged from Klimmendaal and come home to Malden. There I receive a warm welcome from family, friends and neighbours. At the Strengen, I start working on my recovery. For a fortnight I sleep downstairs in a hospital bed and the room turns into a real sea of flowers. Especially from neighbours and friends, I receive many flowers. I could start a flower stall. I receive many visitors and celebrate Christmas extensively in the town Elst at my daughter's home.

Until it becomes too much … In early February 2022, the line snaps; I spin around and call for help, but it is difficult to help me at that moment. I am, however, able to have a one-off consultation with the psychologist at Klimmendaal.

A major relapse sets in, but fortunately it doesn't last too long, My wife, my buddy, and children suffer. Sorry about that, I can't do anything about it. That fucking sepsis too. I seem like a different person, impatient and pushy, I'm not like that.

A lot of stuff has to go, I suffer from a big tidying frenzy, dragging everyone ...

After 3 weeks, things improve again and I become calmer. From then on, I try to distribute my limited energy better together with occupational therapist Lidwien. Finding the right balance is and remains a real challenge. One activity a day is the goal, but sometimes it becomes too much. Then I need to recover for a day.

With the help of Idelette Nutma, an expert by experience in the field of sepsis, things are getting better physically and mentally. Her advice helps me a lot. I can always go to her if I have any questions. Many other social workers are also there for me. I get help from a physiotherapist, an acupuncturist, an occupational therapist and a coach. I count myself lucky to have such a good healthcare system in the Netherlands with very committed people.

The recovery is a big wave, good and lesser weeks, the energy is still not stable, but we remain hopeful. And after a lot of crying together, and crying again about what the future will bring us, something inside me turns. I want to move on, but how I don't know then, but very different ... if Wilbert is two point zero....

On 16 August 2022, we write a letter to the urologist because I continue to struggle with my grief and anger towards the Radboudumc. After all, in my opinion, a mistake was made there, that is where the misery started.

Malden, 16-08-2022

Dear Dr.,

This letter concerns my husband Wilbert Kruijsen. As you know, he was admitted to the ICU of the Radboud hospital on Saturday 28 August last year with urosepsis as a result of a bladder examination performed on Wednesday 25 August 2021. During his stay in the ICU, you or your colleague visited regularly to see how he was doing. Later, during a check-up appointment, my husband and I discussed with you the possible cause of this septic shock.

You told us that you had never experienced this before and could not give a real cause. Since Wilbert is still struggling with a very low energy level, he asked me to put the following question, which we did not ask before, to you.

Now that he can still do almost nothing after a year, it really bothers him how things went then at the Urology outpatient clinic. His appointment was scheduled at 8am, after an hour he was still sitting in the waiting room. The nurse on duty told him there was no urologist present and that she could perform the medical examination. She indicated that she had 27 years of experience. Experience with what did she not indicate.

Our question is whether this nurse was competent to perform this medical procedure. Would it not have been better to make a new appointment so that a urologist could have done this operation?

Wilbert does feel that something went wrong during the treatment because he experienced it as rather painful.

We would like to hear from you soon.

Kind regards, on behalf of Wilbert. Mieke Daalderop

Soon afterwards we receive an answer from the Radboudumc, which of course cannot
obviously cannot take away our sadness, but does bring some reassurance.
The reply from the Radboud does not take away my grief, but it does give me more clarity. I do not want to sue them, that won't get my health back. I want to put my energy into recovery. But, in one fell swoop, I did become an older man.

'10 April 2024. Just back from check-up at Kidney Diseases. Wilbert's kidney function and blood values were found to be excellent again. Because of the stable good results, the nephrologist discharged him from hospital and referred him to the GP for future check-ups. Another step in the right direction, hurrah! So says Mieke in an app to our family.

On 1 April this year (2024), I tell Mieke and the children that it is over. The winter I had spent almost three years in is over. I don't want to experience this ice age again.
Only then will I have the feeling myself that I have really overcome this crappy disease. That I am at a level I can accept. The old me I am no longer, I will have to go through life with my physical and mental limitations.
Many around me, Mieke, children and all the peds and doctors had been telling me for some time that things were still progressing, but I didn't notice and feel it SELF.
On 1 April, and this is not an April Fool's Day joke, I **SELF** felt it.
This winter, this terrible ice age, I have overcome. A hurrah rises in all, a sigh of relief, even in all acquaintances, neighbours and friends.
On to a summer, on to a time full of warmth and love around me. But that is not easy after all. Was my earlier statement on 1 April a so-called April fool after all?
Yet summer just won't come. Rain floods the Netherlands, including Malden. Our garden is sometimes almost flooded after a fat rain. But there is also something else in my personal life that doesn't let summer come, and that is the terrible turmoil of the past few months.

For almost three years, we have been tinkering with jacking up my physical constitution.

I now also notice that something is wrong in my brain. Of course, I felt and noticed this before, but it is becoming very clear now.

In the beginning, I had to learn everything again. Especially typing text for the books I have written does not go without a struggle. How many times I have to rewrite the words that form in my brain and want to put them down on the keyboard. I think I have rewritten every text as many as four times. That there is something wrong with my brain was evident at the time. The former GP did **not** want to give it the term **‘acquired brain injury’ (NAH)** then in 2023.

On 18 June 2024, we are at the psychiatrist's office and she does coin these words. Sadly, but it's no different. In September, I took a four-hour test (NPO: Neuro Psychological Examination) at the Radboudumc. In October, I got the results. That there is demonstrable damage is clear from this test. Besides NAH, it also mentions PICS: **Post Intensive Care Syndrome**. See below.

With this indication, more help doors can open for me. Apart from the shaky walking and more physical discomforts, it is an injury that will be difficult if not impossible to get over. I will have to give it a place.

But what exactly is NAH?

acquired brain injury (NAH) *is damage to the brain that occurred after birth. This could be from an accident, a brain tumour or a cardiac arrest, for example. Brain damage changes your life. You often do not become as you were before the injury. This has major consequences not only for you, but also for the people around you. In the Netherlands, around 140,000 people are affected by brain injury every year.*

What are the consequences of noncongenital brain injury?

The consequences of non-congenital brain injury depend on which part of your brain is damaged and how severe the injury is. This is different for everyone. So everyone also has their own symptoms. Yet there is one similarity for everyone with brain injury: the injury turns your life upside down.

Common complaints are:

- *Physical problems, such as walking badly or not being able to see anymore*
- *Frequent headaches and rapid fatigue*
- *Difficulty concentrating*
- *Difficulty communicating because you can't get out of what you are saying or don't understand what the other person is saying*
- *Be easily irritated or angry*
- *Having psychological problems, such as mood swings or delusions.*

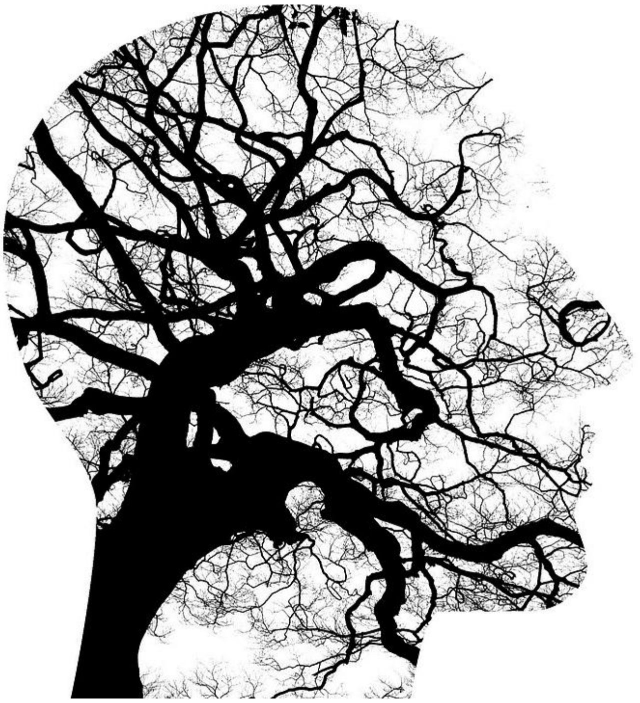
Living with non-congenital brain injury

The injury often changes your life dramatically. It takes time to learn to live with noncongenital brain injury. Both the person affected and their loved ones have to cope and get used to the new situation. This can be compared to a mourning process: you say goodbye to your old life.

Friendships and relationships with non-inherited brain injury

Many people with brain injury are angry more often, tired and depressed more quickly and suffer from forgetfulness. Communicating also becomes more difficult. These behavioural changes can put pressure on your relationships and friendships. By including your partner in the treatment, he or she will learn to understand you better. Explain your situation to friends and acquaintances so they know where your limits are

(Source: handicap.nl)



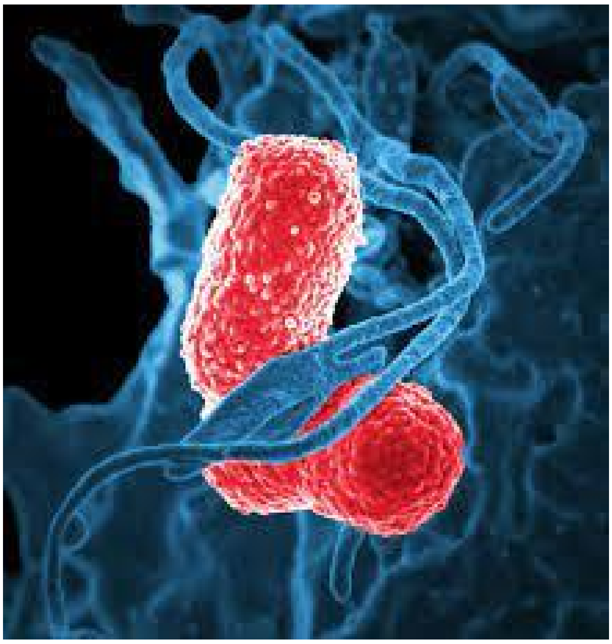
Post IC Syndrome

Visiting the Radboudumc on 16 October 2024, one of the conclusions of the examination I did there a month ago was that I also suffer from the so-called **Post IC Syndrome (PICS)**.

PICS includes the new or worsened symptoms that arise as a result of critical illness and intensive care treatment.

PICS consists of physical, cognitive (absorbing and processing knowledge, thinking, memory, talking) and psychological problems (anxiety, depression, post traumatic stress syndrome) and reduced quality of life. This may already manifest during intensive care treatment, such as ICU-acquired muscle weakness. If a former ICU patient experiences only psychological problems, or cognitive or physical, PICS is also present.

(source: ICconnect.co.uk)



CONSEQUENCES OF MY SEPSIS

How does sepsis affect me and my loved ones? Not only me, my own person, is affected by this sepsis. Mieke, our children and other loved ones, too, have to find a way to cope. And that is by no means easy.

A painful conclusion is that things will never be as they were. The sepsis has lasting consequences for me. Here are some of the consequences.

- **Walking**. In the rehabilitation centre, grandchild Teun ran faster down the corridor than I could keep up with in my wheelchair. Almost three years on, I still walk unsteadily. I no longer use the rollator indoors, but outside the house it is still my crutch. I drag my right foot. Did the IC affect my brain after all?

- **Talking**. Fortunately no damage according to the speech therapist, but talking is slow and difficult and when tired it is even less. My energy runs out quickly.

- **Muscles**. Thanks to fantastic physiotherapists, I walked past the bars a bit after rehabilitation. Physiotherapists in Malden and a fall prevention course give me self-confidence. The wheelchair will eventually be handed in for a walker, the ‘grandfather buggy’. Now I walk through the house without means, I do slouch but we might get that out too.

- **Cycling.** My passion. The four bikes in the garage have been done away with. It is now cycling on a tricycle. I am extremely happy with my Easy Rider, my tricycle. I get everywhere again and cycle a lot. See elsewhere.

- **Driving a car.** I no longer dare and am advised against it. Last year, in Mieke's absence, I ‘secretly’ drove around the neighbourhood. Technically I get by, but am slower in my reactions. I realise that my driving can put others in danger. For long distances, I do depend on others. So unfortunately, no more car for me. In 2025, I will therefore not renew my driving licence.

- **Easily irritable.** I have certainly not been a joy to my loved ones. Sorry, I couldn't and can't do anything about it. Maybe it's due to my character, greatly magnified by that crappy sepsis. My moods do get suppressed by antidepressants, which I started taking on the advice of experts, including

Idelette Nutma-Bade and a neuro-psychiatrist. Anno May 2024, I started reducing them. The side effect hyperactivity that sometimes occurs with me may be caused by these anti-depressants. There could also be other causes. Maybe there is damage to my brain after all. For now, the psychiatrist at the Radboudumc does give the diagnosis of **NAH**, Non-congenital Brain Injury. Tests should reveal that further. In June, I will get exercises to stimulate my brain again. After all, that too needs to be maintained by the body.

- **Sensitive.** I am/was sensitive to (loud) noises, to speed; suffer a lot from abdominal pain/obstipation and many headaches.

- **Memory loss**. Referred to the memory clinic at Geriatrics for this. A Neuro Psychological Examination (NPO) is done lately.

- I had **no taste** during the first year; I ate to survive.

- My **fine motor skills** are gone, caused by tendonitis on my fingers. Cause is unknown according to the physiotherapist. Can't have anything to do with the sepsis either. But just osteoarthritis and wear and tear.

What can I still do and what do I enjoy?

- Enjoying my caring Mieke, my children and their entourage.

- Enjoying my grandchildren, Teun, Isa and Elin.

- Enjoying my friends and neighbours.

- Being able to tinker and work wood again, despite the lack of fine motor skills. Among other things, I made a mobile fence and a workbench, and a mobile kitchen and a fence for Jan and Charlotte.

- Gardening, e.g. cutting grass and planting chicken garden with rose bushes and various separate trees.

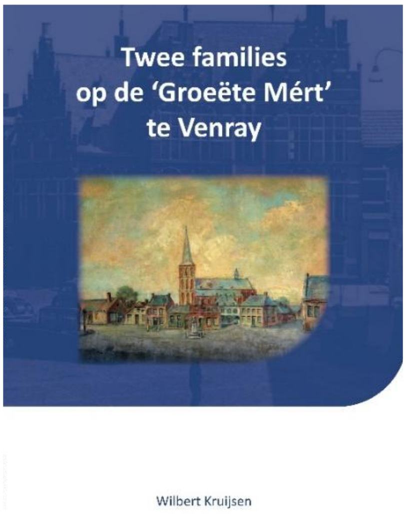
- Enjoying the plants and birds in our garden.

- Enjoying my tricycle. It makes me independent, I can go out into the countryside again. In May, I even cycled up and down to Venray. That does me a lot of good.

- Enjoying my friends from the Stuban70 group. Every month we get together.

- I advise Jan and Charlotte with their large garden in Weurt. It soon becomes clear that they really have green fingers.

- I started writing. Having collected a lot in my working life as a librarian, I now feel the need to start writing, resulting in a few books.



The physical recovery did not go without the help of some wonderful people

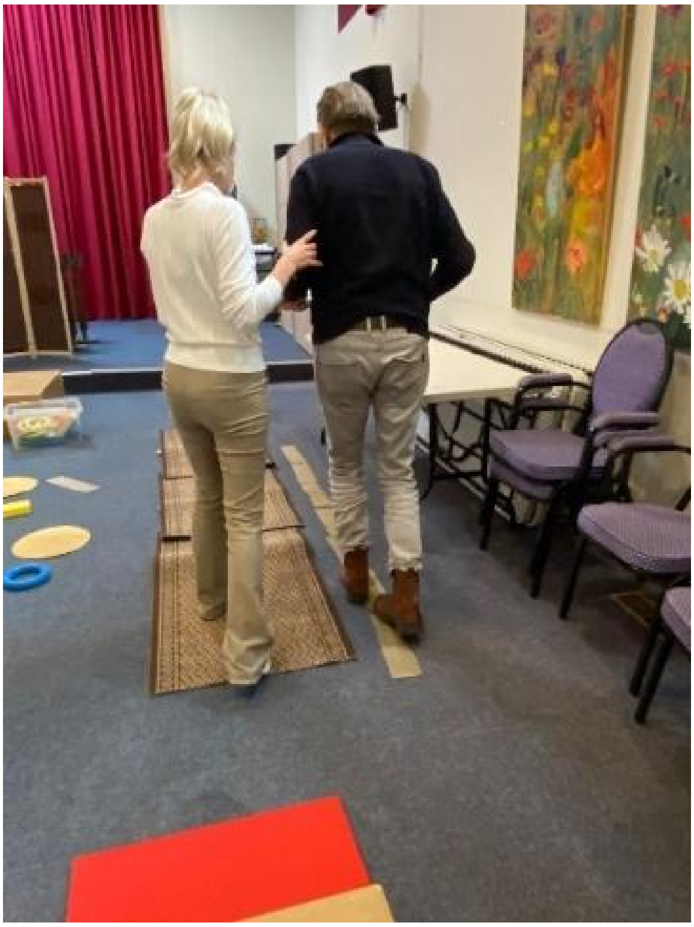
- The weekly massage of neck and back by Imke.

- Acupuncture by Hessel.

- The very wise lessons of occupational therapist Lidwien.

- Intensive physiotherapy from several physiotherapists.

- A fall prevention course given by the fanatical, but oh so involved Judith.



- In 2024, I will exercise twice a week for an hour under Judith's guidance, together with a group of enthusiastic men and women.

What a mistake all can cost, apart from the many physical and mental discomforts. I made a rough calculation of my shots.

Global costs

- Admission Radboud Academic Hospital Nijmegen (2) from 27 August to 14 October 2021. 49 days, including the first 10 days in coma in the ICU (1).

- Admission rehabilitation centre Klimmendaal (3) in Arnhem from 14 October to 8 December 2021. 66 days.

- And that's not counting the many trips by taxi, ambulances, private; as well as the many treatments by physiotherapists, acupuncturist, masseur, etc., etc., etc.

Global costs in euros

Re 1: Intensive Care, level 1. 10 d. x 2500 p/d = 25,000 euros

Ad 2: Total admission Radboud 49 d. x 1000 p/d = 49,000 euro

Re 3: Klimmendaal 66 d. x 3000 p/d = 198,000 euros

Total 272,000 euros

CONCLUSION: DON'T WHINE

Easier said than done. It is a process of trial and error, of accepting and crying that life is not like it was before the sepsis. I will no longer walk across an ancient Roman bridge as I did so often on my Camino journeys.

On the one hand glad they saved me in hospital, on the other, I now have to learn to blend in and live with the discomforts, and even disabilities, that sepsis brought me.

The following are some events, whether in chronological order or not. Events that made me realise that despite all the misery that sepsis brought me, there are certainly some fine and precious events.

I still want to cross that old bridge again, but as a Wilbert 2.0, I have no other choice.

For centuries, people have been building bridges. Bridges are solutions to obstacles, literally hurdles in dada life, to get from one side to the other. I came across the above Roman bridge while walking the camino with friends.

I have to adapt, enjoy fun and sociable things that life brings me, eat with friends, have drinks and play with friends and enjoy my grandchildren.

But also my surroundings, with whom I am living this, will have to realise that I am not the same as I was before 2021. But my motto is **Don’t Whine ...**

‘struggle for life’ turns into the ‘struggle with life’

Don’t Whine ... Don’t Whine ..., but understanding and speaking is slowing me down. I will have to hit the brakes. I often experience understanding, I can no longer do everything with my limited energy and slow response. An example: I write, earlier in 2022, why I cannot attend.

'Dear friends, dear Mieke, and dear football parents,

Unfortunately, unfortunately, I cannot be there again this time. I am not going to be able to eat and be merry with you. Not that I'm depressed, but I don't feel the energy. The past year, in which I tried to recover together with Mieke, children and friends, has been so successful that I can do a lot of things again, am not bothered by ambient noise, have shown and taken many initiatives, such as a birth sign for Isa, collecting rainwater, a work of art in the garden, and last but not least, have written a real book.

In 2023, Mieke and I lost eight people who were very dear to us, family and very close friends and acquaintances; that just happens when you get older, it is actually a phenomenon that comes with life.

We also experienced many good things, such as the birth of our grandchild Isa with whom we are very happy, and the joy we experience from our little friend Teun, who is only too happy to visit grandma and grandpa Malden. He recently discovered grandpa's 3-wheeler. Well we are going to make use of that, a trolley behind my bike offers many possibilities, such as shopping, going on holiday, and going out with the grandchildren. Mieke thinks everything is so bad for me, I think it's even worse for her, suddenly being faced with an old man. She tries her best, sometimes it becomes too much for her. We cried a lot. Relieves they say, for some others it doesn't.

We will have to get used to the changed situation, to a future that will be different for us. Next year we will have been together for 50 years, and we will continue that, till the end !!!

You are a source of support for us, take good care of Mieke and each other. Your friend Wilbert, who is far from being rid of you.'

Wilbert

Old-Stuban meeting, May 2022

Every last Friday of the month, a group of friends, Stuban70, meets at café Daen in Nijmegen city centre. We know each other from the 1970s, when we all played badminton at university. It is a close group of friends who support each other through thick and thin.

***Don’t Whine*,** in July it's time again for the famous Nijmegen Four-Day Walk.

Nijmegen Marches, 2022

Nijmegen Marches, 2023, where son Jan walked the 50 K every day

Don’t Whine… on 17 July 2022, **Isa,** the daughter of daughter Niki and her boyfriend Jesse was born. My happiness, and certainly theirs, couldn't be better.

Being grandparents one more time! With me in the role of reading grandpa for now, and with a ‘grandpa buggy’. Meanwhile, Isa is already 2 years old, a very funny and good-natured girl.


ISA

Don't Whine... Teun has discovered my tricycle in the garage. He can't be kept off it anymore. Earlier, I thought of attaching a sturdy seat for him on the back, but in the end we bought a bike trailer, which has several functions. I can use it to run errands, transport grandchildren and we can go on cycling holidays together again.

Don't Whine ... we held a big party ourselves in July 2023 at the Raven in Heumen. It was a very nice party with nice speeches, and fun, crazy acts.

MIEKE
70 JAAR!

&

WILBERT EN MIEKE
50 JAAR SAMEN!

Tijd voor een feestje!

Zondag 2 juli
vanaf 14:00 uur

Landgoed Bergzicht - De Raaf
Rijksweg 232 in Heumen

Laat je weten of jullie komen?

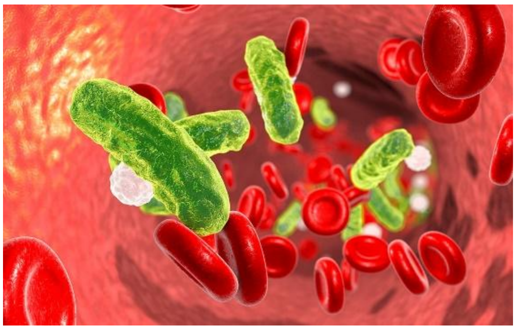
Cadeau idee:
✉ voor een weekendje weg

On 22 April 2024, **Elin Willy** was born. She came into the world healthy, this second daughter of Niki and Jesse, sister of Isa. Definitely a reason not to **‘Whine’**.

ANNEXES

What exactly is sepsis?

Sepsis, is a life-threatening derailed infection reaction of the body, accompanied by organ failure. It is still a very unknown syndrome among the Dutch population.



SEPSIS, THE URGENCY OF A LASTING ALLIANCE BETWEEN GOVERNMENT, INSTITUTIONS AND CITIZENS

SepsisNet is a foundation with the aim of:

- Increase knowledge of sepsis among the public and healthcare professionals
- Ensuring it is recognised in time and can be treated optimally as a result
- Promote multidisciplinary (after)care
- Result: improve survival rates and quality of life of patients with sepsis

Sepsis veroorzaakt **meer doden** dan prostaatkanker, borstkanker en verkeersongevallen **bij elkaar**

Sepsis is doodsoorzaak № 1 op de intensive care

1 op de **5** sepsispatiënten overlijdt

Idelette Nutma-Bade on LinkedIn: Yesterday, 09-05-2024 programme Op1 paid attention to sepsis. Prof Peter Pickkers (intensivist and researcher at Radboudumc) gave a clear explanation of sepsis and the signs to recognise sepsis early.

Former Member of Parliament Leonie Vestering put her finger on the sore spot in terms of not recognising sepsis in time (by her GP) but also in terms of a good example of a nasty long -term complaint namely neuropathy.

Fedde's story illustrated that we sometimes wrongly think in the Netherlands that we 'do it very well' but that things often go wrong around sepsis. In the harrowing example of 20-month-old Fedde, we see how (the possibility of) sepsis is often not taken into account enough, with all its (sometimes fatal) consequences.

The question: ‘Could it be sepsis’ can help citizens to make the (GP) doctor extra alert for sepsis.

Other table guests including former minister Ed Nijpels, and outgoing education minister Dijkgraaf also asked interested questions.

Many an eye was opened to the fact that it is simultaneously so common (60,000 patients/year), life-threatening (10,000 patients die per year) and yet so dramatically unknown!

It is always too short to do justice to all aspects but we were able to highlight the need for more sepsis awareness (also in terms of the consequences and impact on our society) in a special gathering of (former) politicians, and also with an appeal to the government (verbatim by Leonie Vestering and by Peter Pickkers)!

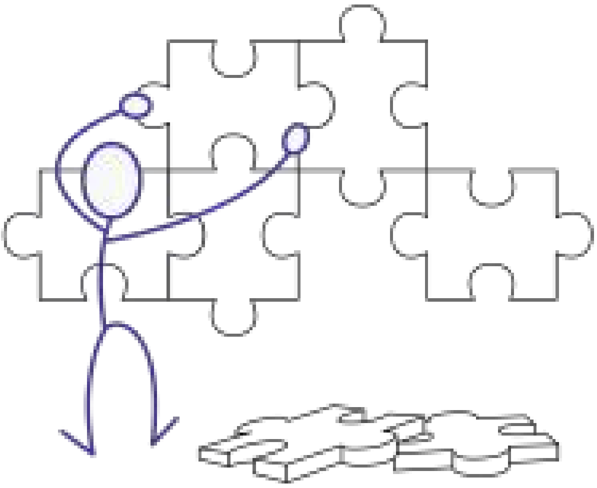
This, we expect, will start setting things in motion. We were also able to have a chat with Minister Dijkgraaf afterwards.

Many thanks to editor Frank in het Veld, Charles GROENHUIJSEN and Carrie ten Napel for the very involved way they prepared the content of the programme with us.

You can watch the broadcast back via:

https://lnkd.in/dFqQDtZZ

For Leonie Vestering's story in the Sepsis Alert Book, see : https://lnkd.in/dPJ585w3



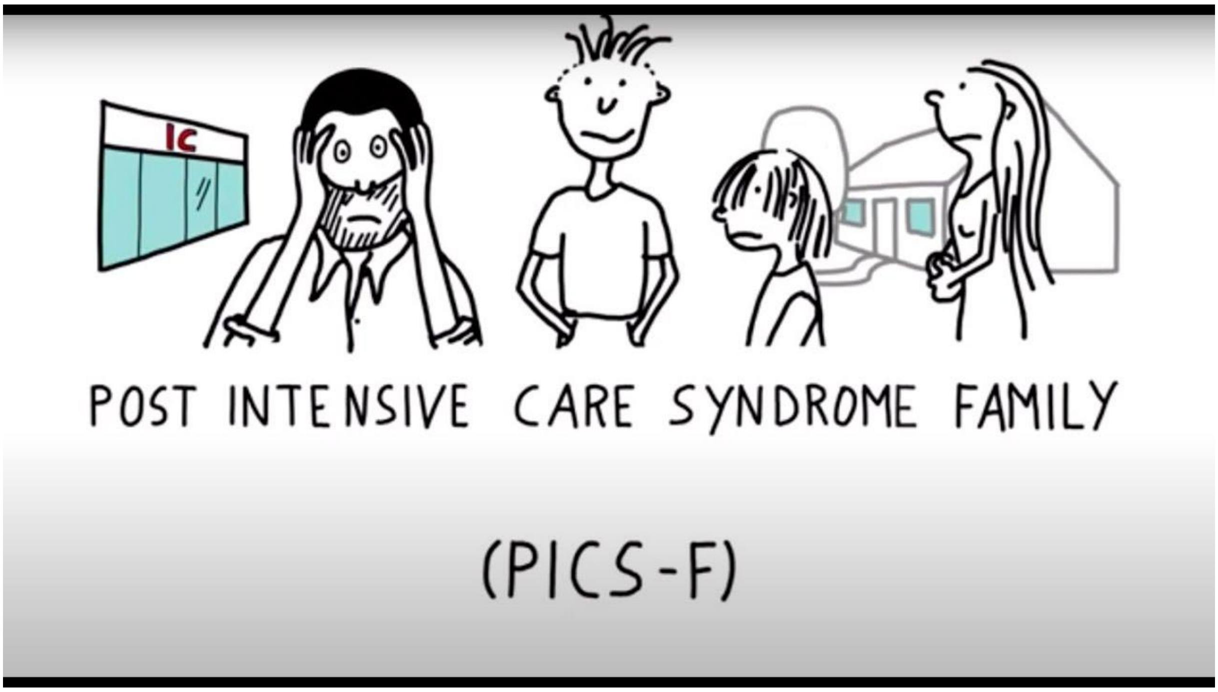
A lot of money is needed for research and information about sepsis. Do you feel involved?

Also see: www.sepsis-en-daarna.nl and www.sepsisnet.nl.

What happened to Idelette Nutma-Bade: an interview

Idelette (51) developed blood poisoning (sepsis) in 2007. The cause was the Hantavirus, which she had developed during an earlier holiday. Idelette: 'I thought the worst was over, but it was yet to come. A few hours later, I became dizzy, had a very fast pulse, I became increasingly short of breath and started coughing up frothy fluid…

Read the entire interview on the Internet at: https://www.sepsis-en-daarna.nl/wp-content/uploads/2021/06/Interview-Vereniging-Hersenletsel-april-2019.pdf



Sepsis and beyond, the Post Sepsis Syndrome

Sepsis is a profound syndrome and is life-threatening in all cases; without medical intervention, patients will die. According to new calculations as published in the article [Societal Costs in the Netherlands]() *(by a team from the UMCG), on 22 January 2024, some 60,000 people a year in the Netherlands are affected by sepsis. Some of these patients are in Intensive Care but many are treated for sepsis in the regular ward. The number mentioned is an estimate, even though it has been carefully calculated. However, because no registration of sepsis takes place, we therefore do not know exactly, but it is clear that the previously estimated number of 35,000 patients with sepsis/year in the Netherlands is now completely outdated. There is also an urgent need to revise the view that sepsis is 'only' an acute syndrome.*

Sepsis as a major disruptor, the Post Sepsis Syndrome

Sepsis is a multi-system disorder; it affects many systems in the body. Those effects are not the same for every patient but often have such an impact that recovery is A) prolonged and/or B) results in multiple residual symptoms and/or loss of function for more than half of patients: called post sepsis syndrome. However, there is (still) a persistent lack of knowledge among the public and professionals around Post Sepsis Syndrome even though a lot of literature has already been published on it. See, among others, Fleischmann-Struzek's study in JAMA (Nov. '21) which showed that 75% of patients, both those in and out of ICU, experience new complaints in physical, neurocognitive and/or mental areas. There is, therefore, a need for further dissemination of this info. Read the whole article: '[Epidemiology and Costs of Postsepsis Morbidity, Nursing Care Dependency, and Mortality in Germany, 2013 to 2017]()'

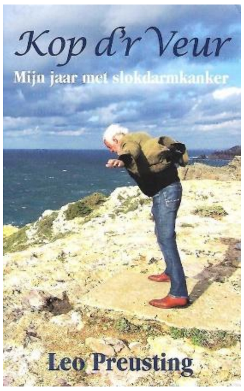
Importantly, doctors and other health professionals need to be aware of the complexity of the syndrome and that the impact can be felt in multiple areas. See image below. Source: the article ‘Understanding Post-Sepsis Syndrome: How Can Clinicians Help?’ (see here for a Ned. summary) published on 29 September 2023 in the Journal of Infection and Drug resistance. The illustration in the article lists many aspects of dysregulation and impact but not all. Hormonal control, gut flora and the functioning of the autonomic nervous system may also be disrupted. The latter can result in Orthostatic Intolerance, of which POTS is an example (explained further below). Below, we further explain some of the aspects of Post Sepsis Syndrome.’

To read the article further, see...... https://www.sepsis-en-daarna.nl/post-sepsis-syndroom/

Key Sources of information and literature read

- **Kop d'r Veur. My year with oesophageal cancer.** Leo Preusting. Publisher Boekenbent, 2013.

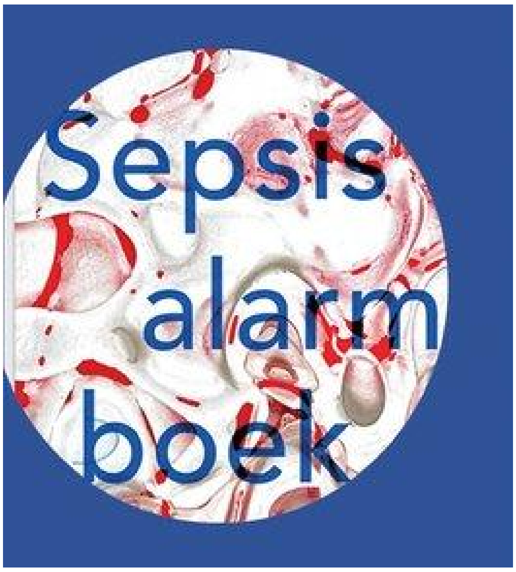
In January 2011, Leo Preusting (Nijmegen, 1953) was diagnosed with oesophageal cancer. From then on, he was immersed in the world of cancer, death, hospital and treatments. After radiotherapy and chemotherapy, he finally underwent surgery in which the oesophagus and a large part of the stomach were removed. A so-called tube stomach was made from the remaining part of the stomach. In Kop d'r Veur, he meticulously describes the events of the months from the first symptoms to the beginning of the post-surgery recovery period. Chronologically, remarkably direct and sometimes with humour, he shows what changes in the life of someone who suddenly becomes a cancer patient. Determination and an unprecedented positive belief in a good outcome have guided him through this difficult phase in his life.



- **Once upon a time. 't Leve in wa songs. Frank van Osch**. Brabant-based documentary filmmaker and singer-songwriter in-a-way. Using his own-award-winning-songs, he leads us through his musical life, telling us about dreams, family, friends and about the merciless finish line. A human story of love and grief and melancholy and hope. An ode. Here's to life!

- **SepsisNet** is a foundation that aims to: Increase knowledge of sepsis among the public and healthcare professionals; Ensure that it is recognised in time and can be treated optimally; Promote multidisciplinary (after)care; Result: improve survival rates and quality of life of patients with sepsis.

- **Septic shock. Idelette Nutma-Bade**. A practical support for (the consequences of) severe sepsis and ICU admission. Publisher Boekscout.nl, 2012. 354 pp.



- **Sepsis alarm book. Idelette Nutma-Bade.** 2023. 62 pp. Sepsis Alarm Book (digital), to share (easily) with your doctor and or acquaintances and family! The Sepsis Alarm Book was released on 13 September 2023. Beautifully designed by Lot van der Vegt (an ex-sepsis patient herself, see also her own story in the book) and made possible by a donation from Jack Lotz who, by the way, lost his wife to a sepsis that was recognised too late. This valuable volume, to which numerous (former) patients, relatives and experts contributed, aims to show in compact form the impact of sepsis but, above all, to convey to the government the urgency of a national approach. The volume provides a valuable overview of facts and figures and the consequences. Sepsis needs to become much better known to the public, and a national plan of action, including a campaign is needed. Will you help spread the knowledge in this way? You can do so very easily because: the digital form of the book is great for sharing anywhere. It is a browsable version, very easy. Make use of it! You can share the link directly: https://digitaalpubliceren.com/sepsisendaarna/18802/