Chapter 1

After years of non-stop work, the two men finally found themselves with some free time on their hands. Having sold their company, they could now relax and take a break from their busy lives. Since their home in Ray-sur-Saône was only a few hours' drive from the south, they decided to embark on a short trip. Their plan was to take it easy and enjoy some luxury hotels whenever they felt like it.

One of the highlights of their journey, as always, was the beautiful medieval town of Aigues-Mortes. The two men had been there before and always relished the experience, especially the food. On a previous occasion, they had settled on a terrace and ordered the "steak tartare," a dish made of raw chopped beef served with accompaniments. When the waiter warned them about the raw meat, they brushed it off and expressed their interest in the recipe. As it turned out, the dish was prepared by the owner, who had recently won a competition with his "steak tartare" being voted the best in France.

The chef/owner came to their table to prepare the dish, which tasted exceptional, with delicate nuances of capers and good white wine.

This experience remained etched in their memories, and they couldn't resist returning to Aigues-Mortes to relive it again.

In mid-April 2015, as the warmth of spring began to displace the cold of winter, Hans and Peter drove carefree through the French Alps. The weather was pleasant, not blisteringly hot like in the summer, but still comfortable enough to enjoy the drive. As they journeyed, they unwittingly passed the spot where a co-pilot had deliberately crashed a Germanwings plane in a horrific suicide attempt, killing many innocent people. The thought of it made Peter, who had a passion for flying small planes, feel particularly uneasy. The idea that someone could take so many lives with such disregard was beyond comprehension.

Despite having experienced bouts of winter depressions and feeling lost in the past, Peter never considered suicide. Instead, he often grappled with existential questions about the meaning of life. With the help of cognitive therapy and antidepressants, he had learned to manage his mood and avoid falling into the depths of depression. However, lately, he had been dealing with a persistent flu that just wouldn't go away. Although the coughing and other symptoms seemed to have abated, he noticed a strange "wobbling" in front of his eyes, which made him tire easily. He attributed this to a small growth in his inner ear that had damaged his right balance organ a few years ago. Even though he knew he should see a doctor about it, he put it off for now, hoping that it would eventually go away on its own.

After wandering for about ten days, they decided it was time to return home. The journey back to Ray-sur-Saône went smoothly, with no delays or hiccups along the way. However, a week after returning home, Peter's health took a turn for the worse. He began experiencing vague symptoms that could have been due to the change in weather from the warm south to the colder climate of Ray.

One chilly evening, Peter lit the fireplace to warm up the house, even though it was late in the year. He knelt down in front of the fire, his right knee pressing against the ground, the instep of his right foot flat on the floor. The following day, he felt pain on the top of his foot, and it started to swell considerably. The swelling looked severe, unlike anything they had seen before. As it was the weekend, they decided to go to the emergency department at the hospital in Gray.

At the hospital, the attending physician examined Peter's foot but couldn't find anything specific that was causing the pain and swelling. The doctor suspected it might be a case of tendon sheath inflammation and ordered an X-ray and blood test. They left the hospital with a prescription for painkillers. Over the next few days, the swelling gradually subsided, and the pain disappeared.

In the days that follow, Peter's health issues continue to escalate. He now experiences a strange, irritating pain behind his eyes, particularly when he looks to the left or right. Growing increasingly concerned, they seek medical advice, and the doctor recommends seeing an eye specialist. However, obtaining an appointment in France can be challenging, with waitlists often lasting several months. In the past, they have sought treatment in Basel, Switzerland, which has no waiting times, but this time they opt for the Netherlands, where they can see a specialist within 10 days.

This timing works out well since they are also planning to travel to Belgium to finalize the sale of their company, PC-Navigo and NoorderSoft, the makers of the inland waterway route-planning program. The sale marks a significant transition for the two men, as their company has been in business for 25 years.

Unfortunately, while in Belgium and the Netherlands, Peter's health deteriorates further. Initially, he experiences pain in his left foot, similar to a previous issue with his right foot, but it gradually worsens throughout the day. Later on, he begins to feel abdominal pain and discomfort after drinking white wine with dinner. His condition worsens, and he feels weaker and has trouble breathing, with the pain in his chest and abdomen becoming more intense. After passing out, he wakes up with excruciating pain, which he suspects may be related to his liver. After reflecting on their excessive alcohol consumption, Peter and Hans decide to stop drinking.

After spending a few days in Belgium, despite Peter still feeling unwell, they decide to continue their journey to the Netherlands so as not to miss their appointment with the eye specialist. Luckily, they can stay at a friend's flat in the heart of Amsterdam. However, Peter's symptoms persist, and he remains tired and sickly. Concerned, Hans buys a thermometer, and it reveals that Peter has a fever of 38.5 degrees Celsius. While it offers some explanation for his discomfort, the fever doesn't subside on its own, and they attempt to alleviate it with paracetamol. One evening, they had arranged to have dinner with friends Kees and Guido, but Peter is too unwell to attend. Kees and Guido kindly prepare and bring dinner to their flat, but the atmosphere is tinged with anxiety about Peter's condition.

Upon their return to Ray-sur-Saône, Hans and Peter visit their general practitioner and recount the past few weeks' events, including the eye specialist's inconclusive examination. The doctor is unconvinced and orders another blood test. A few days later, the doctor calls to ask them to come in as the blood values are concerning. During the consultation, the doctor looks uneasy, and suggests they go to the Hematology department at the university hospital in Besançon for further examination. When Hans asks directly, the doctor admits that she suspects a "blood disease" (an understatement for leukemia). The gravity of the situation is apparent, and Hans and Peter's worries mount. At this stage, little can be said for certain.

Hans and Peter make their way to Besançon a week later for their appointment with Dr. Chauchet, a hematologist. The doctor conducts an extensive intake, asking Peter numerous questions about his symptoms, medical history, work experience, and lifestyle. During the visit, the doctor draws a significant amount of blood and takes a bone marrow biopsy. Peter is pleasantly surprised by the minimal discomfort he experiences throughout the procedure, which could be attributed to the doctor's skillful technique.

Despite the optimism of quitting drinking, Peter's health continues to deteriorate. It is now the end of April, and he still feels exhausted and unwell, with a persistent sharp pain behind his eyes when coughing and sneezing. It's challenging for him to articulate his fatigue, but he knows it's draining. He's also lost seven kilos, but Hans hasn't lost a single ounce, suggesting there's more to the story than quitting alcohol.

Chapter 2

In early May, Peter's exhaustion has become so severe that he requires a daily siesta to make it through the day. He's even sleeping for longer periods of time, and on one such occasion, he receives a phone call from Dr. Chauchet, the hematologist at the university hospital in Besançon. The doctor delivers the devastating news that Peter has leukemia, although they won't know the specific type until further lab tests are conducted the following week. In that moment, Peter's mind races, and he's left speechless and unable to respond to the doctor's well wishes for the evening. The diagnosis shatters Peter's world, as he knows very little about leukemia, other than the common knowledge that it is often a fatal disease. He had hidden his fears from himself, dismissing his symptoms as stress from work, unhealthy habits, or simply aging. But now all of his doubts are confirmed. Peter is overcome with emotion and cries uncontrollably. He feels incredibly lonely and lost, as if a death sentence has been passed down. Hans sits beside Peter on the bed and tries to comfort him while asking about the phone call with Dr. Chauchet.

"Why are you so devastated now?" Hans asks.

Peter tries to compose himself as he recounts the news to Hans, but his voice is strained with sobs. Through his tears, he tells Hans what Dr. Chauchet said. Hans, always the practical one, tries to comfort Peter by telling him that it's too soon to give up hope. He suggests they look up information about the different types of leukemia and the treatments available. For a while, Peter sits there numbly, lost in thought.

The two spend the rest of the afternoon scouring the internet, searching for answers. They discover that there are various types of leukemia, and while it's a serious illness, there are treatments that can prolong life or even cure the disease. In a subdued mood, they eat dinner and watch TV, lost in their own thoughts. They retire early, holding each other tightly as they cry themselves to sleep. The days ahead will be filled with tension, and they know that Peter may face a difficult battle.

On the morning of May eleventh, Hans and Peter received the results of Peter's tests in Besançon. It turned out to be a fairly rare form of leukemia called Chronic Myelomonocytic Leukemia, currently in the chronic phase. While it can become acute and requires a heavy and risky treatment, for now it can be managed with medication for a few more years before treatment becomes necessary. Another bone marrow puncture was taken from the hip bone, but Peter had little trouble with it. They left the hospital reasonably optimistic, but Peter still felt a gnawing sense of uncertainty.

Upon returning home, Hans immediately started writing an email to friends and acquaintances, but Peter was lost in thought and didn't pay much attention to the content. The email was sent out that afternoon.

> *Greetings everyone,*
>
> *I hope this message finds you all well. I wanted to update you on the latest developments regarding Peter's health. After a long wait, we finally received the results of the blood tests. Unfortunately, the diagnosis is Chronic Myelomonocytic Leukemia (CML), which comes with some question marks and requires further tests, scans, and blood work to be done throughout the month of May. Despite the uncertainty, we are grateful to report that the*

specialist has confirmed that there is no immediate threat to Peter's life.

We are trying our best to take things one day at a time and stay positive. Some days are better than others, but we're trying to make the most of May despite the circumstances. We won't be able to go on vacation for the time being, but we're finding other ways to have fun and keep our spirits up.

Peter sits staring at the message on the screen, feeling uneasy. He had a different impression of the visit to the hematologist that morning, and he's not sure the hematologist saw it positively. Then he notices a mistake in the message: the abbreviation for the diagnosis is wrong. It should be CMML, not CML. He immediately searches the internet to compare CMML to CML and finds a much less optimistic outlook. In the Netherlands, only about 60 new cases of CMML are diagnosed each year, and the prospects for a cure are not as favorable as with other types of leukemia.

Hans realizes that they are in a very different situation than they thought. He wants to send a follow-up email immediately, but Peter is hesitant.

He worries that it will create too much panic and confusion. They decide to wait and send a new, corrected email the next day.

Peter has a restless night, sighing and worrying. Reluctantly, he gets up in the morning and goes about his usual routine, walking the dogs and running errands. At the supermarket, he realizes how much money they've spent on alcohol over the years and how it adds up. Back home, he and Hans work on a new email to send out, one that they both agree on. They send it in the afternoon:

> *Yesterday we received the results from the hematologist in Besançon, and unfortunately, the diagnosis is chronic myelomonocytic leukemia (CMML). We initially thought it was a less severe form, but after doing some research online, we now realize that it's a relatively rare and serious type of leukemia. If you're interested in learning more, you can check out this website: http://www.info-over-kanker.nl/.../zeldzame-vormen-van-leuke.../ (look for the CMML section).*
>
> *While we don't want to be overly pessimistic, we also don't want to sugarcoat the situation. The fact is that there are no guarantees, and*

the treatment options can be quite challenging. We'll be undergoing various tests throughout May, including PET scans, gastro- and colonoscopies, and numerous blood tests. Depending on the results, we may need to consider chemotherapy, stem cell transplantation, or a combination of both.

Despite all this, we're trying to stay positive and maintain our quality of life as much as possible. We'd also like to let our friends and family know that they're more than welcome to visit us, as the company is a welcome distraction. We have plenty of space, and we'd love to see you. Our next appointment with the hematologist is on June 8th, assuming nothing unexpected happens before then.

As of late, every day is a struggle for Peter as he finds himself constantly exhausted. Simple tasks require great effort and he needs to rest once or twice just to make it through the day. Occasionally, he takes his dogs for a walk to the nearby meadow, but even this is a challenge. Although the meadow gate is only thirty meters away from his house, Peter struggles to make it there and needs to take a break before returning due to the path's slight incline.

As the month draws to a close, Kees and Guido, Peter's friends who previously cooked for him and his partner in Amsterdam, come to visit. Peter feels a surge of happiness with their arrival, but his fatigue prevents him from doing much for them. His exhaustion dominates his life at the moment. Despite this, Peter enjoys spending time with them, lounging on the couch and chatting. Everyone in the household works hard to ensure Peter is as comfortable as possible during their visit.

As May comes to a close, Peter's energy levels dwindle, and even simple tasks become burdensome. Walking to the nearby meadow with the dogs is a struggle, with the gate only thirty meters away from the house. Exhausted from the walk, he has to rest before returning to the front door, which rises slightly uphill. Although Kees and Guido's recent visit brought joy to Peter, he is limited by his constant fatigue. He can hardly do anything for his guests, but he relishes their company and the chance to chat with them while relaxing on the couch. The entire household makes a concerted effort to ensure Peter is as comfortable as possible.

As the end of May approaches, Peter's condition deteriorates further. He wavers between hope and despair, hoping that tomorrow will be better but resigned to the reality of his current state. Despite his love for cooking, he has not been able to indulge in his favorite hobby for a while as standing in the kitchen is too taxing.

When the hematologist calls to cancel the upcoming appointment in early June, Hans speaks up on Peter's behalf, insisting that the appointment goes ahead despite his poor health. Although the leukemia is still in the chronic phase, treatment is postponed, and the doctor prescribes vitamins and Prednisone. Overwhelmed by the situation, Peter is often unresponsive and despondent, unable to prepare for the possibility of death. In an effort to lift his spirits, he calls Wijnand, his first love and a longtime friend, and finds solace in his encouraging words.

A week later, Peter's condition takes a turn for the better. He wakes up with a newfound sense of happiness, feeling more energized than he has in weeks. The medication he's been taking appears to be working like magic, allowing him to concentrate and go about his day without the constant need for rest. He's even able to indulge in his favorite hobby once again and cook for himself and Hans. This improvement in his health provides a glimmer of hope for the couple.

To add to their joy, they receive a visit from a friend of Hans, Bea, who has survived three bouts of cancer and is an inspiring example of optimism. The weather in Ray-sur-Saone is gorgeous, and the trio enjoys a string of pleasant days, basking in the sun and getting a lovely bronze tan. To keep their loved ones updated on Peter's progress, Hans and Peter regularly send out email updates.

On June 9, 2015, Peter writes:

> "*This week we had another meeting with the hematologist about the best approach to his leukemia. It was very enlightening, and he proposed a strategy for the coming period, based on the finding that my energy level can be boosted with medication. It is important that it seems the leukemia is still in the chronic phase and, if it remains that way, with medication, the energy (read quality of life) can be kept reasonably stable. Those medications consist of corticosteroids to suppress fatigue and a very light form of chemotherapy that is intended to keep the leukemia "chronic" for as long as possible.*

Our original assumption that bone marrow transplantation would be started as soon as possible is thus incorrect: the hematologist explained that the disadvantages of this approach do not outweigh the benefits for now. At least a 6 to 7-week hospitalization is required, followed by about a full year of follow-up treatment, and the risk associated with transplantation is considerable; if rejection of the donor stem cells occurs, it is the end of the road...

I also feel a lot better thanks to the corticosteroid treatment that started last week, and now I can work on improving my physical condition, which has deteriorated quite a bit over the past few months. So, the goal now is to keep the leukemia as chronic as possible, to monitor it regularly (which involves taking blood samples), and to maintain my energy level with Prednisone at a level that allows me to lead a reasonably normal life (including outings and possibly even longer trips in the future).

It is true that the possibility of the leukemia becoming "acute" again and making transplantation unavoidable still hangs over

> *our heads like a sword of Damocles, but we find the advice not to rush into transplantation to be a good and well-founded one, so that is what we are aiming for at the moment. Thanks to the extra energy, the pleasant weather, and the great moral support from you and our friends here, life is good in Ray-sur-Saône at the moment. Therefore, we enjoy every good day, and luckily there are more of them since last week than bad days!*"

However, the situation is not entirely carefree. Peter and his loved ones are on an emotional rollercoaster as his condition occasionally worsens, causing doubts and worries to resurface. They scour the internet for any additional information about the disease and potential treatments, which is not a source of happiness. Despite the lengthening days, they still retire to bed early and often find comfort in cuddling with one another. There are moments where they simply look at each other and break down in tears.

Facebook has become a valuable tool to communicate with many people at once, sparing them from the need to write lengthy letters or engage in prolonged phone conversations. Sadly, Peter's parents are no longer alive, but he takes solace in knowing that they do not have to experience the stress and anxiety of this difficult time.

This period is marked by its highs and lows. June 15, 2015 is one of the high points of the rollercoaster ride: Peter shares a post on his Facebook timeline to express his happiness in that moment:

> "*The cuttings of the wisteria seem to be doing well and we have a friend of Hans visiting who is having a great time with the beautiful weather. She's sitting comfortably on the terrace, sunbathing with the dog by her side. What a wonderful time, I'm enjoying it again!*"

The hematology department is taking all necessary precautions in case treatment is required in the near future. To eliminate the possibility of other types of cancer contributing to Peter's condition, a battery of tests has been scheduled. These include several scans, a gastroscopy, and a colonoscopy, with the latter set for June 18th. Unfortunately, the preparation for the colonoscopy is proving to be challenging for Peter, as he has to consume 2 liters of a mixture to cleanse his bowels, leading to another restless night. However, he is relieved that the tests will be carried out under anesthesia, as the gastroscopy is known to be quite uncomfortable.

On June 18, 2015, Hans writes a message to friends and acquaintances:

> *"Delivered 'empty and clean' to the hospital in Vesoul early this morning. Today are his LAST two tests (there have been more than ten altogether by now!) to determine whether CMML is the only cause of his symptoms. If so, we'll be rid of it until July, hopefully - except for the weekly blood tests, of course, and except for an attempt by his ENT doctor to improve the 'wobbling' in his eyes (which is actually somewhat unrelated). If all goes well, he'll be back home by late afternoon...".*

In the afternoon, the internist who conducted the Gastroscopy and Colonoscopy paid a visit, but he proved to be an aloof figure, offering very little information and evading most of Hans and Peter's questions. Peter complained of significant throat pain, but the doctor brushed it off, blaming it on the anesthetist. Frustratingly, they were unable to reach the anesthetist to get to the bottom of the issue, and they were left in the dark until the laboratory results arrived. The only notable thing the doctor had to report was that he had removed a few polyps from Peter's intestine.

Unfortunately, Peter's health took a turn for the worse in the days following the examination. He had little energy, and the throat pain only intensified, making matters worse. As if that weren't enough, he began to develop bruises on his lower legs, a probable side effect of the Hydrea medication that was being used to keep his leukemia in check. The situation was starting to look grim.

Every week, Peter's blood was drawn at the district nursing center a few villages away, and the results were available online in the afternoon. Though they were able to view the results themselves, they couldn't interpret them accurately. But one week, the latest test results were alarming, with an urgent message from the hematologist in Besançon. The number of white blood cells per ml had spiked to 90K, dangerously close to the lethal threshold of 100K. It was evident that the leukemia had progressed to the acute phase, and something needed to be done immediately. The hematologist wasted no time finding a hospital bed for Peter, but unfortunately, there were no available spots in Besançon. Eventually, it was decided that Peter would be admitted to the hospital in Vesoul the following day. Despite the momentary panic, Peter was relieved, as he hoped to at least recover somewhat in Vesoul.

Chapter 3

The hospital in Vesoul may be new, but the quality of care is not up to par. Although Dr. Faure is welcoming and tries to put Peter at ease, medication errors occur frequently. Peter must remain vigilant and continually verify that he is receiving the correct dosage of medication. Despite the increased dose of Hydrea, the nurse only brings two pills instead of the six Peter requires. When Peter speaks up, the nurse brushes off his concerns, assuring him that the computer has the correct dosage. Only after Peter insists does she double-check and discover that a much higher dosage is needed. Peter is grateful that his mental faculties are still sharp enough to catch such mistakes."Luckily," Peter thinks, "my brain is still functioning properly."

Sleeping has become a major problem for Peter. The pain in his throat is so intense that he can barely swallow. It appears that something went wrong during the gastroscopy, but the Vesoul hospital has not taken any action to address the issue. They claim that there are no available throat lozenges or pain relievers like paracetamol. Feeling helpless, Peter reaches out to his friend Hans at 3 a.m. in a cry for help, stating that he can no longer bear the pain. Hans responds immediately and procures paracetamol and throat lozenges from the nearby night pharmacy. The nursing staff on duty receives a stern reprimand for their lack of action.

After a few days, there is some good news from Peter. He texts Hans, exclaiming, "Yippee, the chemo is starting to work!" His leukocyte count has decreased from 90,000 per ml to 60,000 per ml, indicating a positive response to treatment. However, the rest of his blood counts, including red blood cells and platelets, are also dropping, making it difficult for wounds to heal and causing Peter to bruise easily. His lower legs are beginning to develop unsightly blue-black spots. Nevertheless, there is some hope, as a drop in leukocyte count to 20,000 per ml would provide some relief.

In the afternoon, Peter's general practitioner, Monique Couillaud, contacts the treating physician to inquire about his condition. This attention gives Peter a sense of comfort and satisfaction, despite the cause for concern about his deteriorating health.

The nursing staff at the Vesoul hospital leaves much to be desired, but the food is even worse. In an effort to provide some relief, Hans brings avocados, nectarines, shrimp, and wine. They are a welcome addition to the unpalatable hospital fare.

The coffee is equally unappealing, prompting Peter to venture out to the bar downstairs at the visitor's entrance for a decent espresso. He attaches the IV to a walker and heads out to the terrace to enjoy some sunshine, attempting to inject a bit of quality into his final days.

Peter has been unusually quiet lately, unable to speak due to the intense pain in his throat. Despite promising that an ENT specialist would visit, the medical team has not followed through, seemingly prioritizing other matters. Something is seriously amiss, but no one is taking action.

A visit from Peter's nephew, Dave, who has driven 700 km from the Netherlands, brings some comfort. He is visibly worried about his uncle's condition and provides assistance to Hans in the garden while visiting frequently. During one emotional visit, Peter confides in Dave his concerns about his survival and asks for some soft white bread called "pain de mie" to ease the pain in his mouth. The gums are sore, and the roots of his teeth are sensitive to pressure, making the hard rolls served in the hospital a disaster.

Toward the end of the month, there is a glimmer of hope as the white blood cell count returns to 29,000 per ml. However, the bone marrow biopsy reveals that the leukemia has entered the acute phase, presenting a difficult choice. During the initial consultation with Dr. Chauchet in Besançon, Peter had stressed the importance of quality of life over quantity. With only two weeks to live without treatment, Peter and Hans decide to pursue treatment with the possibility of a stem cell transplant, if a donor can be found. It is a last-ditch effort to fight the disease and cling to hope.

He is transferred to Besançon in the afternoon of June 29, 2015. The transportation is by medical taxi, but Peter is barely aware of the journey and spends most of the time drowsy. That day, Hans writes on Facebook:

> *Peter is changing hospitals! Because the rest of his treatment is better done in Besançon, he is being transferred there by ambulance today. The treatment, aimed at reducing the amount of leukocytes as much as possible, will continue at the Hopital Minjoz in Besançon, and the preparations for the bone marrow transplant will also take place there. So later today or tomorrow, a new phone number and more information will follow.*

In Besançon, Peter is lovingly received. What a difference from the cold treatment of the nursing staff in Vesoul! The room where Peter will stay for the coming period is a sterile room. All of his clothes go into a hermetically sealed bag that Hans can take home later.

Access to the room is strictly regulated for everyone: hairnet on, sterile gown, mask, and shoe covers. Upon entering, hands must be disinfected with alcohol gel. This also applies to the nursing staff and doctors. As soon as Peter is settled in bed, the first procedures begin. A catheter needs to be placed in the shoulder blood vessel behind the clavicle. Blood will be taken and chemo administered via the catheter. Hans has just arrived when the nursing staff announces that they are going to place the catheter. Hans has to go to the waiting room, and it is expected to be done within half an hour. Peter has to lie flat on his back for the catheter to be inserted. He is covered with blue sterile cloths like in an operating room. He must also wear a mask over his mouth, and his head is turned to the left because the catheter is inserted on the right side. A blue sterile cloth is also placed over his head. Fortunately, he does not suffer from claustrophobia, but it is stuffy. Initially, the catheter seems to be going well, but then it stalls. After about ten minutes, a nurse pulls back the blue cloth and explains that there is a minor complication. Nurses come and go, discussing a lot amongst themselves, which Peter can't follow. After another 20 minutes, Peter receives reassuring news. He tells the nurse that they should alert Hans and explain what is happening to prevent him from worrying too much. After an hour and a half, there is still no progress, and an internist is called in. Eventually, things seem to be sorted out, and everything is taped up. A nurse tells Peter that Hans has already gone home because he has to take care of the dogs.

Peter sends him a text message asking him to call when he gets home and that everything is okay. Hans texts back that he is still in the waiting room and very worried.

He enters the room and is close to tears; he is extremely relieved that Peter is still alive. He saw how the nursing staff rushed to the room with a defibrillator and how panic occasionally broke out outside the room. The nurse tearfully told him that she was mistaken when she said that Hans had already gone home. She was convinced that he had left but had forgotten to check the waiting room. Later it was explained that the catheter had been inserted too deeply, which caused a cardiac arrest to threaten. When the catheter is inserted, there is a thin steel wire in an acrylic sleeve. When the catheter is in place, this wire must be pulled back. This did not work either. Eventually, they managed to do it, but it was a terrible day.

On the last day of June, Peter begins his first chemotherapy treatment. He wakes up early at around 6 a.m. and sends a message to Hans, updating him on his condition:

> *"Hi love, had the worst night so far. I kept calling for my throat, and they tried a strong medicine, but it didn't work out. I ended up sitting in front of the toilet, vomiting but thankfully didn't faint. Trying to get things going again with breakfast ;-). My head feels heavy, like I drank one bottle too many*

yesterday. The sun is shining, and I'm determined to get back on my feet. I love you."

Despite his determination, the problem with his throat persists. Dr. Larosa, one of the doctors, explains that the epiglottis is inflamed and may have been damaged during the gastroscopy in Vesoul. Unfortunately, the poor blood count means that the body cannot heal the inflammation at the moment, and they must wait it out. Hans visits Peter during the visiting hours in Besançon for the first time that day. While there will be numerous visits to follow, Peter always feels relieved to receive the message that Hans has arrived home safely. It's a one-hour drive each way on the back roads of Franche Comté, and Peter can't bear the thought of anything happening to Hans.

Wijnand and Jan, Peter's good friends of nearly 40 years, visit him over the weekend. They snap a selfie in the airlock of his hospital room and post it on Facebook with the caption, "Dr. Zhivago and Dr. Oetker." Their visit boosts Peter's spirits, which is much needed since he feels terribly ill and exhausted. Despite his pain, the attention and support from his friends give him the courage to persevere.

The side effects of chemotherapy are taking a toll on Peter's body, and it's becoming more apparent with each passing day. The doctor's explanation of the damage caused by the treatment is brutal: "your intestines from your throat to your anus are burnt. It's like you have a sunburn on the inside." The inside of his mouth is also ravaged by the chemo. Large sores line the sides of his tongue and big blood blisters are visible on his cheeks. Even speaking and swallowing are painful, and he startles suddenly, reflexively biting his tongue or cheek, making the pain worse. He can only hope that it will eventually heal.

Peter is in a daze most of the time, but occasionally he wakes up, his thoughts and senses clouded by the drugs. He receives many medications through the IV, but he's not always sure what they are or why they're being given. He can't sleep either, just dozing off intermittently with his eyes closed. He tries to distract himself from the pain by composing poems, but the lines repeat themselves endlessly in his head, and he can't seem to remember them.

Late at night, he writes a poem on his tablet, his words reflecting his longing for better days:

Wandering through deep valleys,
Memories of completed times arise,
Hoping to reach the incomplete times to come,
I try to avoid the thought of
The incomplete present tense.

Wijnand and Jan paid Peter another visit the following day, providing some much-needed relief for Hans and a source of comfort for Peter. Despite the taboo on physical contact, Peter expressed his gratitude with a small smile. It has been a significant challenge for Peter to maintain his relationships with friends and family due to the effort required to communicate, and he struggles with tasks like writing and visualizing the outcome of renovation projects. Maps are of little help to him, and he struggles to orient himself using them. Peter's memory doesn't rely on images, but rather on stories and events. Despite these challenges, the morphine in his system has resulted in a shift in his perception, allowing him to recall memories from his childhood in vivid detail, like a sort of video playing in his mind's eye. These memories are not always pleasant,...

Peter is slowly emerging from the depths of despair, inching his way up centimeter by centimeter, as he puts it. Though still tentative, he hopes to continue along this trajectory. Wijnand and Jan had returned home a week ago, leaving Peter to look forward to Kees' weekend visit during designated hours. Kees and Guido had recently returned from vacationing in Dordogne, and stopped by to see Peter on their way back. It was strange for Peter to see Kees fully dressed in a face mask, apron, and hairnet. Nevertheless, their conversation was intense and a welcome distraction from the monotony of the ward. The two reminisced about their shared experiences fighting for gay emancipation, temporarily forgetting their current circumstances. While the visitors have to take the necessary hygiene measures, Peter did not have to wear a face mask. During a lull in the conversation, Kees stares pensively at Peter, leaving him to wonder what was going through his friend's mind. Peter is frequently confronted with the image of himself in the bathroom mirror every morning, which never fails to shock him.

While Quatorze Juillet is a national holiday in France, life at the hospital continues unabated. Peter has managed to sleep reasonably well for four nights in a row now, giving him hope that the worst is behind him. His troubles with mouth sores have been addressed with a new mouthwash, which should be more effective. Unfortunately, it leaves a terrible aftertaste that persists for hours, making it difficult for Peter to eat or drink anything afterward. Thankfully, a helpful nurse has a clever solution: rinsing with cola. Surprisingly, it helps to remove the stubborn fungal plaques, making a significant difference for Peter.

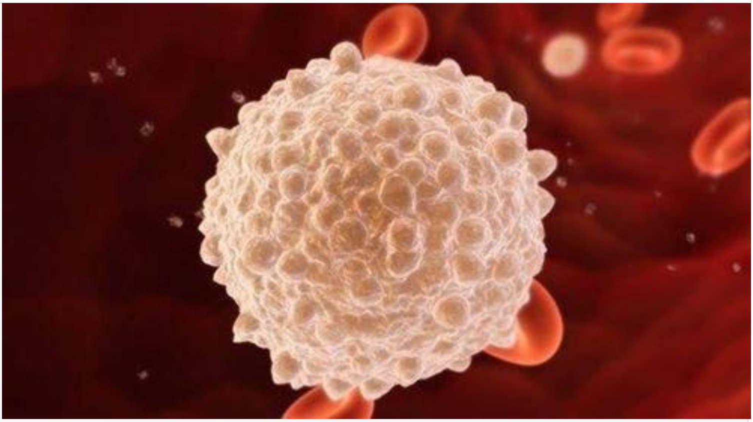
In recent days, Peter has noticed that his hair is falling out in increasingly larger clumps, which is not a pleasant experience. Before it becomes too unsightly, he decides to ask nurse Philippe to shave his head. Using a small hair clipper, Philippe chatters away about his pets as he works, and Peter is left with a smooth, hairless head. As he examines it, he notices some grooves that he hasn't seen before. These are likely from an accident he had when he was sixteen, where he rode his moped into a lamppost and suffered a severe concussion, leaving him hospitalized on the verge of a skull fracture.

At the moment, Peter's body still isn't producing enough blood, so he requires regular transfusions or platelet bags. These must be administered with strict controls to ensure the correct patient receives them, including providing the patient's name, date of birth, and place of birth. After three weeks, Peter's blood production begins to improve, offering hope for his recovery. However, the crucial question remains whether the cancer is still present in his blood or whether it has been eradicated.

While there are no complications or infections, Peter could potentially go home for a few weeks at the end of the month. However, this prospect still seems distant to Peter. He continues to experience regular vomiting and severe gastrointestinal issues, with defecation being particularly painful due to the burning sensation of sour diarrhea. Despite his efforts to mitigate the discomfort with wet paper towels, it is an ongoing challenge. To make matters worse, the "Japanese shower" that was previously available for patients to rinse themselves off has been removed due to hygiene concerns, leaving Peter without any effective relief for the time being.

Every morning, Peter shares an update with Hans on how he slept and any discomforts he experienced. Today, he had some good news to share - the orange he ate actually had flavor! He could faintly taste the orange in it again. It's a small victory, but it gives us hope that his sense of taste and smell will fully return. Thankfully, the worst of the stomach and intestinal issues seem to be behind him now. It's a relief to see some progress in his recovery. Hans writes on Facebook:

> Here is a white blood cell; Peter Leunis Feenstra currently has 900 of them. If he has 1,500, he can go home for a little while (and until that moment, he is bored to death!).



Now that the production of white blood cells is getting back on track, the throat is finally starting to heal. It has taken a long time, but the pain is getting less every day. Speaking is still not easy, but Peter is now understandable again. By the end of July, the number of white blood cells has risen to a sufficient level to be able to go home, but another problem arises. Hans writes:

> *We already knew about homophiles and francophiles and such, now we also know about "neutrophiles". These are components of the white blood cells, which in Peter's case appear to be not in order yet. What a bummer! Because now his chemo break has to be postponed until enough neutrophils are measured in his blood.*

On August 1st, 2015, Peter is finally able to leave the hospital. As he makes his way through the corridors, he encounters unfamiliar faces, all of whom greet him kindly as if they've known him forever. He can only recognize them by their voices, which feels like a surreal experience. Before leaving his room, he had to don a face mask, slip-on shoes, a hair net, and a gown. Once he exits the department, everything he's worn is disposed of, except for the face mask, which he must keep on until he's in Hans' car. Walking to the hospital exit is an enormous task, requiring a step-by-step approach. When he finally reaches the exit, Peter sits down while Hans fetches the car. Feeling the breeze on his cheeks is a strange sensation after so long inside. With a bald head, he experiences the sensation of wind on his scalp for the first time. As he gets into the car, he removes his face mask and breathes a sigh of relief. As Hans accelerates to match the speed of traffic, everything outside flashes by at a dizzying pace. Even 50 km/h feels like a hundred. After about thirty minutes, Peter starts to get used to it and can relax, gazing out of the window. The two friends don't say much, but the joy of being outside the hospital together is palpable.

Upon arriving home, tears well up in Peter's eyes as he takes in his surroundings. The dogs lovingly circle around his legs, sensing his unsteadiness on his feet. Rather than going straight to bed, he takes a seat on the couch in the living room to process the overwhelming flood of emotions. Hans, noticing his partner's emotional state, offers to make a cup of coffee, but it only leads to another crying spell as Peter realizes he still cannot taste anything.

To help Peter acclimate to being at home again, they decide to take it easy and avoid visitors for the first few days.

Chapter 4

When a childhood friend inquires about his well-being, Peter responds with cautious optimism. "I'm doing reasonably well," he says, before sharing the news that he has recently returned home after a five-week hospital stay. The next round of chemotherapy is scheduled in ten days, and while it will also take about a month, Peter believes it will be less severe than before. He hopes that the last treatment will be in October, and if all goes well, he will be cured. However, he acknowledges that certainty won't come until spring of 2016, and in the meantime, there are many uncertainties that could go wrong.

Despite Peter's current condition, his fear of what's to come is growing. He wishes that the ordeal were over already, and the looming dread of having to go through it again is suffocating. Nevertheless, there is little choice but to take the next step. Peter knows that if he wants to live longer, he must continue with the treatment.

Usually, Hans takes care of the cooking. He has come up with a simple menu:

- Mixed salad
- Ravioli with Roquefort sauce
- Dessert

Peter's elation at standing quickly dissipates into a need to sit down as he finds he can't stay upright for more than five minutes. Nonetheless, he feels a sense of triumph at accomplishing something "normal" once again. Though his taste buds are improving, he still has Hans taste his food for safety. After Hans gives his seal of approval, Peter breathes a sigh of relief, realizing that he can still rely on his culinary expertise. Life seems to be showing him a kinder side at last. Feeling a bit better, he's eager to start doing things again. He hones his flying skills by practicing with his flight simulator, X-Plane, and a set of instruments that connect to the computer, including a steering console, foot pedals, throttle and flaps controls, and more. The program is impressively realistic, especially in terms of weather integration.

After only ten days at home, they are struck by a stomach flu that leaves them both bedridden and exhausted. Hans takes the initiative to write to their friends and acquaintances, updating them on their situation:

> *"This week's 'sickbay' in Ray: since Tuesday, I have been struck by a stomach flu and/or food poisoning, which is not so clear, and since yesterday, Peter Leunis Feenstra is also lying next to me: 39-degree fever, nausea, vomiting, in short, 'the works'. Fortunately, the telephone advice service of the CHU Besançon works perfectly. With 4 extra pills, he is back on his feet EARLIER than I am..."*

By mid-August, they had both recovered from the stomach flu, with Hans still experiencing some discomfort, but Peter feeling completely fine. Peter's good blood values granted them a few extra days to enjoy before he returned to the Besançon hospital for his second round of chemotherapy, also known as consolidation therapy, aimed at preventing a relapse of leukemia. Despite feeling uncertain about what to expect from the second round of chemotherapy, Peter was grateful for the time he had to recuperate and prepare.

Fortunately, some good news had come from the hospital. Although two potential donors had been found, they were unfortunately rejected by the professor due to incompatible stem cells. However, a new donor had been found, raising Peter's hope for a successful transplant. Without a compatible donor, the entire treatment plan would be rendered useless.

In the third week of August, Peter returned to the hospital to begin his treatment. The schedule was unusual, with five days of chemotherapy in the hospital followed by five days at home, and finally 10 to 15 days of quarantine back in the hospital. Despite the challenging schedule, Peter remained hopeful and determined to beat his illness.

At the end of August, he will return to the hospital for a period of aplasia in the sterile room. Aplasia means that the bone marrow no longer produces blood. That also has to be artificially added, platelets, blood transfusion (red blood cells, etc.). The day after the administration of the consolidation chemo, the number of white blood cells drops very quickly. According to plan, it will not drop completely to zero but to 500 per ml. The vulnerability to infections is then very high, so even the food is served sterile. There is little taste in the food. Peter is allowed to use some salt, but pepper is forbidden because it is not sterile. The only thing he still enjoys eating is pasta with tomato sauce.

The next morning, Peter is sitting in front of the TV; he doesn't feel like reading. He woke up feeling very tired, and things are not going smoothly. At quarter to twelve, he feels an uncomfortable pain in his chest that obstructs his breathing. It hurts when he takes a deep breath, and his left shoulder also feels unpleasant; it's a nagging pain that radiates backwards to below the shoulder blade. He waits for half an hour, but then he reports it to the nurse who happens to come in at that moment. Everything is done: his heart is immediately checked with an electrocardiogram, and an X-ray of his lungs is taken, but it doesn't show anything. Hans got quite a shock; he had just come to visit when they were performing the electrocardiogram. As a precaution, antibiotics and painkillers are given right away, but it doesn't really help. Peter can't find a position that makes the pain bearable. Lying down doesn't work, sitting up straight is the best he can do. At 7 o'clock in the evening, another lung scan is performed. The result comes later that night: nothing is found. Slowly it becomes more bearable; they added an extra shot of painkillers. He sleeps well that night, and the pain is largely gone. It's still there, but in the background. It's a mystery where it came from, but he finds it very reassuring to see that the nursing staff responds very adequately. In fact, Peter has had this kind of unexpected pain in his body all his life. As a child, his mother used to say, "Sleep on it, and you'll feel better in the morning."

Peter fights boredom with reading. Nowadays, there is a wide range of e-books available. He reads "The Ship's Boy" by John Boyne. He puts it aside halfway through, as he finds it not as good as the other books Boyne has written. He also watches TV regularly; the hospital only has French-speaking channels, which is good for his French. The nursing staff on the "soins intensifs" department is generally highly educated, and they enjoy speaking a foreign language. Occasionally, Peter is confronted with an almost unintelligible "Franglais". It's well-intentioned, but Peter asks them to speak French.

After days of inactivity, there is movement in the number of white blood cells. This morning, they stood at 700 per ml. But the platelets are still very low: 20,000, so they need to be added again today. And suddenly, there's good news: the donor has been approved. The donor is from Belgium and turns out to be a 10/10 match for a stem cell donation.

A so-called "chambre implantable" is placed in Peter's chest. This is done at a private clinic nearby. It is a kind of subcutaneous box that is connected to the veins. This makes it easy to make a connection for administering medication and taking blood. During the placement of the CI, the surgeon turned out to be a colleague pilot at the flying club where Peter takes lessons. During the operation, they only talked about flying. Apparently, such specialists can be occupied with very different things during an operation. The subcutaneous box has become an unsightly bump, but hopefully, it will work well.

Every once in a while, the connections on the infusion and tubes need to be replaced. The nurse who was supposed to do it must have had her Monday morning, as she forgot half of her supplies and had to keep going back for something. It was very inconvenient because every time she had to put on a new gown and mask. In the end, it took three-quarters of an hour when it could have been done in ten minutes. Peter became grumpy and impatient. When Hans tried to put things into perspective, he got a scolding from Peter:

"*Well, you're not the one lying here,*"

was his sharp response. Hans decided to remain silent to avoid making things worse.

Today, the white blood cells have also increased in number to 730. That's not impressive yet, but it's enough to avoid having to eat sterile food. The veins in Peter's palms were very blue in the morning, usually a sign that a blood transfusion is needed. And sure enough, two bags of blood were pumped into his body in the afternoon.

In mid-September, there is good news: Peter's leukocyte count has increased to 1300 per ml. This means that he can go home soon. They are still waiting to see what the neutrophils will do; they were the culprit during the first chemotherapy. The transfusions, Zarzio, and antibiotics are being stopped. Peter feels good in his body; he moves smoothly and has no pains or discomforts. He has ultimately withstood the consolidation chemotherapy with great ease. He has not experienced any unpleasant side effects. The latest myelogram (bone marrow biopsy) shows no affected cells. The doctors are enthusiastic and optimistic, saying he has gone through the treatments so far 'brilliantly,' which Peter feels is true. When he was admitted in late June with acute myelomonocytic leukemia, he was more dead than alive. Now he feels very good, almost like "before," just a little faster tired. He has to go back to the hospital in a week to prepare for the stem cell transplant, which will take place on October 14th. The idea of being locked up in a sterile room for 4-5 weeks is very hard for him. When the time comes, he will surrender to it, but now it's a nightmare. He clings to his dreams and plans for the future. In the spring, Peter wants to get his pilot's license and perhaps fly around the world in a few years. In the short term, he plans to use his time in the hospital to program an EEG headset in a less commonly used programming language, which might make it easier to operate devices and such with mental commands.

Well, first, he still has to survive this phase.

Chapter 5

On Wednesday, October 7, 2015, Peter is admitted again to the University Hospital of Besançon, now for the final chemotherapy and for the definitive bone marrow transplant (or rather, stem cell transplant, as that is what is transplanted - bone marrow stem cells from the blood of a healthy donor).

The day begins badly. One of the dogs, Bâbord, has been sick for a while and now seems to have no more life energy left. Hans takes Peter to the hospital and as soon as he returns to Ray-sur-Saône, he takes the dog to the vet. It doesn't look good. The animal is completely exhausted and lethargic. Hans calls Peter to discuss. They decide to put Bâbord to sleep.

During the first two days, various preparatory tasks are carried out: connecting the infusions to the chambre implantable, performing a large number of tests that can serve as a reference for comparison before and after the transplant, and administering preparatory medication. During these two days, he also prepares completely for a stay of several weeks in the sterile room. The computer, tablet, phone and accessories have been sterilized, installed and connected. Everything that is needed for the stay in the next 4 to 6 weeks, both to entertain himself and to take care of himself as best as possible. The days start counting again, or rather, it's time to start counting down.

On October 9, 2015, the preparation for the allogeneic stem cell transplant begins. Peter receives a cocktail of Fludarabine and Busilvex. "It's going to be some party," he thinks somberly. But, as he reminds himself, it's all for the best. The big question now is how tough it will be. Will he survive?

On the 14th, he will receive the stem cells. Yesterday was a rest day with no appointments scheduled, so he took the opportunity to write a thank-you note to the donor, a young woman from Belgium. That's all they know about her; strict anonymity is observed. Peter writes the note in Dutch, which the hospital can translate into French.

Dear donor,

I would like to express my gratitude for taking the time to donate stem cells. I understand that the procedure is similar to giving blood, *but it takes longer and may be somewhat uncomfortable. I hope it was not too much trouble for you.*

In early May, I was diagnosed with a serious form of leukemia. At first, it seemed that the disease would remain "chronic" for a prolonged period. However, it quickly progressed to the acute phase, and without treatment, I would have only had a few weeks left. Fortunately, the first chemotherapy treatment was successful. The doctors then began searching for a suitable donor, and fortunately, you were found! This gives me the opportunity to continue living my life: getting my pilot's license, finally going on vacation, and hopefully accomplishing a few more things in the field of computer science. We all hope that the stem cells will take root and that I will once again be a healthy person.

I will always remember this moment with gratitude and respect.

With warmest regards,

Peter

Today Peter receives the first dose of chemotherapy. For some reason, he has also been given Valium. He feels like he's chugged a bottle of gin. "Well, that's a good start," he thinks. During the preparation at home, he had put a large collection of music on his tablet. After dinner, he listens to some retro music; cheerful songs from Simon and Garfunkel. Then it hits him; he's here alone, with softly beeping machines in a bizarre and strange environment. He bursts into tears; how sad and hopeless this feels. Despite his many supportive friends and Hans, who loves him very much, he feels lost and lonely. More sharply than ever, he feels deceived by his Christian upbringing. His mother told him as a child, with good intentions, that he should never feel alone because Jesus was always with him. He feels it's a terrible lie; "you have to go through it alone." No matter how you twist or turn it, dying is something you do on your own. Peter tries to rationalize it, but he fails miserably. Eventually, it's a long phone call with Hans that calms him down a bit. Apparently, the Valium was not for nothing.

During those last days before the transplant, Peter doesn't feel much from the chemo. However, he becomes increasingly emotional. He asks the nursing staff if the ward psychologist can come to talk to him. He feels he needs all the support he can get to gather courage again. He spends hours writing and "flying" with the flight simulator, just to pass the time. Then a small straw presents itself; he sees a cartoon of Garfield. He's sitting next to Snoopy on a scaffold, looking out over the water, and says thoughtfully,

> "You know, Snoopy, one day we're all going to die."
> Snoopy responds,
> "Yes, but on all the other days, we don't."

It is an emotional lifeline for Peter to hold onto.

The side effects seem to be absent. Except for a slight fatigue, Peter still doesn't feel much. "But that's still to come," says the nursing staff. And they don't look happy about it.

October 12, 2015, is the last day for administering chemo: two more doses to go. So far, Peter is physically holding up well, there's still only a slight fatigue. But emotionally, he is very fragile. His emotions are lurking in the background and can't be pushed away. Towards the end of the afternoon, preparatory medicines for the stem cell transplant are administered. He feels sick, sleepy, and drowsy. So, he decides to spend as much time sleeping as possible...

The night is an ordeal; every little thing keeps him awake. Sweating from fever one moment, then vomiting on the edge of the bed the next. The nursing staff checks on him every hour, but nothing seems to help. He's relieved when daylight finally comes, as everything seems to calm down a bit. In the morning, he receives SAL (anti-lymphocyte serum) as preparation for the actual administration of the stem cells. In the afternoon, he's given "stimulating agents": corticosteroids, vitamins, and more. During visiting hours, the treatments continue, with Hans by his side. At least, it has the result that he feels a lot better that evening, and he calls Hans in relief.

October 14th, 2015 is "the big day". Friends from the Hematon group on Facebook talk about the day of transplantation as the day of the 2nd birth. Peter is not as optimistic as they are. He feels like he'll just have to wait and see if things will ever be the same again. Nevertheless, he's in top form, thanks to all the vitamins, cortisones, and other medications he's been given. The support and encouraging messages from all his friends also give him a boost. This afternoon at around 2 o'clock, the stem cells will be administered, and he's both anxious and hopeful.

The thank-you note for the donor is ready to be sent through the blood bank. He's happy that this time he doesn't have many visible effects from the chemo. He actually found baldness quite convenient; it saved him a fortune on razor blades. The Hydrea (which he received when leukemia still seemed chronic) caused very ugly blue-black spots on his legs. Now he only has a flushed face as if he's been in the sun too long. On to the next phase!

The staff is very compassionate about Peter's condition. They are aware of the risks and know what's yet to come. They always lend an ear, even when things get tough. They make every effort to cheer him up. After a shift change, it's always "do you remember me?" which can be difficult as they are only visible behind face masks. But Peter recognizes most of them by their voice. This week he also had a conversation with a psychologist about his fears and sorrows. It did him good, and today he feels stronger because of it. He has great admiration for all the people taking care of him. He doesn't know if it's appropriate, but he's thinking of sending a few crates of champagne to the entire team of doctors and nurses for Christmas.

Peter had slept well last night and felt as "strong as a bear" (although he had to hold onto something after walking just five steps). But it seemed like he needed to be even more "boosted" before the planned infusion of stem cells at 2:00 pm. Finally, at around 5:00 pm, the moment had arrived. But his veins had other plans; the IV was blocked. They tried to insert it in his other arm, but to no avail. Eventually, the most experienced nurse managed to place the IV in a thick vein on his wrist, after struggling for what felt like an eternity. Finally, the bag of stem cells began to flow steadily into his veins. It looked just like a bag of blood he had received during transfusions, but this was different. This was supposed to regenerate him from within.

At 5:30 pm, the bag of stem cells was empty.

Now, it is a waiting game…

On October 15th, after the infusion of stem cells, there's not much of a noticeable change at first. But as Thursday progresses, Peter's temperature rises and malaise intensifies. Is it the chemo, or maybe a reaction to the new stem cells? Everything stays within reasonable limits, but the fatigue is as bad as after the first chemo...

On October 16th, the effects become increasingly apparent, and Peter feels worse and worse. He suffers from intense headaches, and it seems like the palms of his hands and soles of his feet are on fire. Most of the time, he lies in bed in a daze. Even going to the bathroom is a huge undertaking, but at least it gets him out of bed for a bit. The treatment during these days consists of alternating doses of Methotrexate and Folinate, administered every other day for about five days. He has no idea what it's for; his body is currently a large biochemical reactor. To alleviate the pain, he receives an incredible amount of paracetamol through the IV, but it also causes him to sweat heavily. It's tough, really tough.

On October 17th, the malaise seems to be slightly less, but he's still exhausted. His voice gives out, and he experiences a nasty tightness and pressure in his lungs. According to the doctors, it's still a typical effect of chemotherapy. During this period, Hans visits the hospital every day, but the visits are brief. Peter is mostly asleep, and it's a struggle to stay awake during the visit. Hans just sits there for an hour.

October 18th: a bad start to the day, after breakfast Peter experiences severe abdominal cramps. He breaks out in cold sweat and almost floods the chair. So back to bed it is. During the daily doctor's visit, it is decided to switch to intravenous feeding to spare the intestines. The rest of the day, he can't do anything at all. Someone even has to come to support him when he goes to the toilet.

19 October: Apparently, Peter was so exhausted yesterday that he actually slept well last night. But his energy level is still extremely low. He carefully makes his way to the bathroom for a cup of tea with sugar. Luckily, there's a chair he can sit on. After wiping his face with a wet washcloth, he stares into the mirror with his elbows resting on the sink. Will he manage to wash the rest of himself too? In desperation, he asks Philippe, the nurse, to help him with the rest. It's like taking four steps back to bed; the marathon is over, now it's time to rest for two hours.

The really nasty side effects, like in July, have not yet appeared. However, extra medications are being administered, including those for stomach cramps, mouth sores, and other effects of the heavy chemotherapy...

In the afternoon, Peter receives an email from the programmer who has taken on the development of 'his' computer program. There is a strange problem with the database processing. As soon as the data is made suitable for the route planner, the names of the waterways appear strangely; there is a space between every letter. Peter has to read the email three times before he realizes that he has seen this problem before. The solution is relatively simple for a programmer. Despite the 'dip' he is in, he secretly enjoys being able to help with this technical problem.

October 20: Today, Peter suddenly feels a bit more energetic. He woke up feeling clear-headed and refreshed after a night with few discomforts. The daily routines, such as visits from the medical team, are not too exhausting. The doctors look at him with a certain expression of "well, well, you've been lucky so far." Of course, there may be more challenges to come, but for now, he feels that he really shouldn't complain.

After taking a bath, he wrote some emails and flew a flight simulator from Schiphol to Eelde via Lelystad. He enjoys practicing radio navigation. He experiences occasional stomach cramps, but they're not really worth mentioning; a severe bout of diarrhea during the flu is worse. For now, he is enjoying himself and not thinking about any potential future troubles. Yesterday was a break day from the heavy medication, so that may have caused this improvement. He will receive another dose of Methotrexate at the end of the afternoon, and indeed, his energy will decrease again in the evening. He will receive one more dose of Folinate tomorrow, and then it will be over.

In the following days, there are ups and downs. Sometimes he can sit in a chair all day, and at other times he can do nothing but lie in bed. Energy slowly starts to return, and he can watch TV for an hour in the evening. However, around October 23rd, a new period of trouble seems to begin: nosebleeds, a rising temperature (38 degrees), and acid reflux. Everything can still be treated with medication, but Peter wonders if these are the first signs of GvHD (Graft versus Host Disease; rejection by the new blood). He will ask about it this afternoon. Fatigue is hitting him hard again, and he is sleeping more during the day than in the past few days.

The trouble turns out to have nothing to do with GvHD. It can occur only after 15 or even 35 days after the stem cell transplant when the stem cells have "taken" and settled into the bones. Starting from day 15 after the transplant, a blood test called "Evaluation du chimérisme" is performed to measure the levels of "own" and "donor" blood. The fever and discomfort are probably due to a virus, bacteria, or microbe. The rack of bottles for the infusion will likely be expanded. Hans and Peter will not know until October 29th (or even later) if the "greffe" has "taken."

Peter slowly realizes how long everything is taking. In early May, he received the initial diagnosis. Then, things seemed to be going well for a while. But then it all went wrong and he has been in and out of hospitals for months, with things only getting worse with intermittent periods of respite. Surviving is more a matter of just breathing than anything else. Every morning is a struggle, with no idea if tomorrow will be reached. At the end of the morning, a nurse comes in to take blood and asks Peter how he is doing. He bursts into tears. He is a small pile of misery, wondering, "How will I ever get out of here? Will I ever be able to lead a normal life again, or is this it?"

When Hans comes to visit half an hour later, Peter has regained a bit of composure. They sit together and cry. Everything is so overwhelming: it has been so long, they have been at this for half a year already, and are likely not even halfway there yet. It only seems to be getting more difficult. Peter's fear of whether he will ever be able to lead a normal life again runs deep. The physical journey is difficult, but the emotional toll is almost unbearable for them at times. Peter has a saying for it: shared pain is double pain. Next week, Peter will talk to the psychologist again, and for now, he seeks distraction. Relaxation exercises and meditation help a bit, but when the body is tied up in knots from chemo and medication, it's not always easy.

One of the sources of the problem turns out to be a mild inflammation of the "CIP", the infusion port that was placed under the skin on Peter's chest. Therefore, it needs to be temporarily deactivated to allow antibiotics to be injected, which requires a temporary infusion. Peter's veins are hard and have been repeatedly punctured, so the placement of the infusion fails three times, resulting in some significant bruising. Platelets and an extra dose of red blood cells are administered. As always, he feels somewhat better after receiving the red blood cells.

Peter cannot eat anything and receives nutrients through the infusion, in large bags of a white, yoghurt-like substance. Occasionally, he takes a sip of water, but not too much, or else he will vomit it back up. He watches his favourite TV programme, "Questions pour un champion."

Slowly, he begins to feel nauseous. Then, he starts to vomit. He reaches for the container that is already prepared, and it comes up in waves. But it's blood! More comes up, and the container is almost full. In a panic, he presses the alarm button. He anxiously wonders if it's an ulcer. How long can someone survive something like this? Minutes pass, and nobody comes. Crying, he continues to press the alarm button. He can't scream because his voice is gone, and they wouldn't hear him anyway. The sound doesn't carry through the airlock that separates the room from the hallway. After fifteen minutes, he calms down a bit. Nothing else happens; it doesn't get worse, and he doesn't faint. He doesn't feel any worse. Finally, someone from the nursing staff enters. They look at the container of blood and say it's not serious. However, the attending physician is called to assess the situation;

he looks at it and says that a vein in his oesophagus has likely ruptured. Another gastroscopy will need to be done tomorrow. By the time night falls, everything is under control again...

October 26th: Peter can only whisper now. The morphine makes it difficult for him to articulate. It seems like he's had too much to drink. Then his temperature is too high, then too low. Vomiting has become somewhat routine and it's usually just mucus because nothing stays in his stomach. One complication piles on top of another. They call it a dip, but it feels like a low point to him. Like during his first chemo in July, Hans and Peter are amazed by the calm professionalism with which the hematology team tackles (and largely solves) all the problems. It's like walking a tightrope.

The nurse announces that Peter is leaving the ward for a gastroscopy. Now it's his turn to be fully wrapped up. A mask, hairnet, sterile gown, and booties over his feet. The taps on the IV are closed and the tubes disconnected as he is wheeled in a wheelchair to another ward. It's cold in the hallway. His feet are uncomfortably cold. In the examination room, he has to lie on a ready-made stretcher, good thing three people are there to help. He gets a weird piece of plastic in his mouth. The doctor says they can't use anesthesia because it would be too risky. The tube with the camera is pressed against his painful throat and at that moment he has to swallow. He sees the screen from the corner of his eye. It's sheer torture. The tube slides down his throat into his esophagus and a lot of air and water is pumped in. Large black twisting streaks are visible on the wall of the esophagus. The doctor says in a satisfied tone that it is indeed esophagitis and that it's not serious. He takes a biopsy of an affected area. It's a good thing Peter is completely powerless because he struggles violently against the pain!

Back in his room, the hematologist comes by. It turns out to be esophagitis. There's little they can do. It will only heal when the production of white blood cells starts up again. Instead of the IV in his arm, he will get a catheter in his groin, but that won't happen until the next few days...

October 29th: The past few days have passed like a fog. The morphine dose was continually increased to combat the pain. Peter has pain everywhere; in his throat and intestines, headaches, his hands and feet feel like they're on fire. Despite the morphine, the pain is intense. Most of the time he lies half asleep, in a state of reduced consciousness. He completely surrenders himself to it: they can do whatever they want.

October 30th The day begins like the previous three, although it may seem to be getting a tiny bit better. Then, during the morning round of doctors, Peter is told that yesterday, 300 white blood cells per ml were measured in his blood, and today even 400! Although these white blood cells could theoretically still come from his "old" bone marrow, the treating team finds that very unlikely. The last chemotherapy has almost certainly disabled that "old" bone marrow completely. So it really seems that it can only come from the transplant. But the real evidence for this will only come next week, when the "chimerism test" shows that the blood is indeed attributable to the donor stem cells. That test is scheduled for around November 4th. However, even if the result is positive, it still does not mean that all the trouble is over: the post-treatment, especially the treatment of rejection symptoms and "graft-versus-host" disease, will still last for the majority of the next six months. But still, this appearance of "globules blancs" is at the very least encouraging...

31 October: Hans keeps a blog and writes today:

> *It seems there is a slight setback in terms of energy and well-being. Despite having slept well, Peter woke up feeling very nauseous and*

unwell. So, today he will take some extra Primperan to fight the nausea and maybe an extra dose of painkillers, which means more sleeping. Meanwhile, the white blood cells have increased to 600. Later in the day, the discomforts ease up a little bit. The nursing staff is still helping us to invoke the "aide sociale" to assist us with the bureaucratic procedures for Peter's travel expenses (because yes, even in these cases, the French health insurance likes to nitpick and fuss)...

1 November 2015: Peter has slept reasonably well. However, he always wakes up several times during the night. The nursing staff comes by at around 3 a.m. to take his temperature and blood pressure, and at half past 5, blood is also taken. His throat, esophagus, and intestines seem to be getting better. At least he has less pain now. It is an upward trend, but it is terribly slow. The doctors warn at the same time against being too optimistic: almost always the first year after transplantation is very difficult. But when they talk about the first year, they apparently expect a second and third year as well? Hans and Peter are hopeful, but the warning

was not for nothing; in the evening, he starts vomiting again and has a terrible headache.

November 2nd: Today is a worse day. A lot of nausea, vomiting without anything in the stomach, and headaches. More medication is given, but it doesn't do much. However, the white blood cells are up to 670 today, which is good news. The visiting hours were not much, so Hans went home earlier as Peter was just sleeping.

November 3rd: Not much has changed. Sleeping is going fairly well; Peter has gotten used to the interruptions. However, the persistent fatigue, nausea, and vomiting are concerning. It just doesn't seem to get any better. Around 10 o'clock, the team of doctors visits again. Peter asks with a desperate look what he can expect in terms of the duration of this misery. They look stern above their face masks. There is nothing to be done, he will have to get through it. There are three possible explanations for the discomfort: after-effects of the chemotherapy, side effects of the morphine, or a symptom of early GvHD. He'll have to tough it out in all three cases. The white blood cells suddenly jumped up to 1000 today, which is very positive news.

November 4th: The treatment for Peter's nausea isn't yielding any results, but oddly enough he's getting used to it. Every morning, he calls Hans to update him on how he's doing. Often he has to pause and say, "Hold on, I need to vomit again." Only mucus comes up since he still isn't eating or drinking anything. During the doctors' daily visit, it's discovered that his white blood cell count has risen again. Not by much, but still. When Peter complains about the persistent nausea, he's told that it's very normal at this stage. They keep reading about the "100 days" after the transplant being difficult and critical in brochures from the hospital here, as well as in all the information available on the internet in the Netherlands. Today is day 21 of those one hundred, so there are still 79 days left. They've added a counter to Hans's blog on the website.

November 5th: Peter realizes that he's never slept so much before. Normally, he's not someone who sleeps in. He actually thinks sleeping is a waste of time. There's so little of it already! Wim, Peter's brother, is in France for a few days. Peter hopes that it provides Hans with some company; he needs it. They come to visit around 1 pm. Peter doesn't have much to offer as company. He falls asleep frequently, and when he's not sleeping, he's vomiting. It's not pleasant for the visitors, but there's not much that can be done about it. In consultation with the doctors, the morphine dosage is reduced, perhaps that will help to alleviate the nausea.

November 6th: Peter thinks morphine is a terrible substance. He has terrible restless dreams. Before the morning washing routine, he has already vomited twice, and even then the nausea persists. The effects of Primperan, a drug for nausea, last no more than 4 hours. Immediately afterward, the nausea returns. Peter becomes despondent. However, his white blood cell count has risen to 1500 in the meantime. He complains about the nausea once more, and they try a new medication. And lo and behold! It works! Peter tries to rally himself for the visit. Brother Wim comes with Hans again, and he wants to show his "lively" side. He manages it, but he's not worth a penny for the rest of the day.

On November 7th, after his morning blood draw, Peter couldn't sleep anymore. It's now half past seven and soon the nurses will come to change his bed and clean the room. His routine is to go to the bathroom to wash up and brush his teeth. They've already finished cleaning the room by the time Peter is still staring at himself in the mirror above the sink. There's a showerhead above the sink that's meant to sterilize the water, and it's regularly replaced. Everything here is sterile. Peter can't smell anything, probably due to the chemo. Even the watery and burning diarrhea he's been experiencing has no smell. After brushing his teeth, he sits there exhausted for a moment. It's quiet in the bathroom. Above the bed are large grates that bring in purified air. Along with the pumps for his medication given through the IV, it creates quite a bit of noise. Not to mention the alarms that go off occasionally when a medication syringe is empty. He looks in the mirror again and sees the face of an old man, thin and wrinkled. He goes back to bed, but the nurses have left it high up. It takes him an extra half a minute to stand before he can lie back down. Luckily, the nausea seems to be absent today. What a relief. During the visit from Hans and Wim, they talk a little about the future. As they talk, Peter's responses become increasingly hesitant. He thinks to himself, "I don't see a future." He goes dark and can only cry.

On November 9th, early in the morning at seven o'clock, Peter gets out of bed to pee. The urine needs to be collected, so he has to stand up to pee. Before he knows it, he has to pass gas, and it didn't come without consequences. He ends up with a dirty pair of underwear and is still experiencing diarrhea. He can't clean himself up, so he has to call the nurses. He's been given a medication for his diarrhea: Smecta. As he prepares to take it, he takes a sip of water and chokes. Before he can grab the vomit bucket (they call it "the bean" in French), it's too late. He vomits all over himself. He's already so used to it that he can laughingly tell Hans over the phone what happened. The period from the transplant until now has been extremely difficult with all sorts of unpleasant complications, but today is a happy moment: he's had solid food for the first time since October 18th. A small piece of bread with jam and a cup of tea.

And the biggest surprise: he was able to keep it down! It's only been a few days since a sip of water came right back up the same way it went down.

The doctors are visiting again and they now see clear signs of mild Graft-versus-Host Disease (GvHD): red patches on the chest. Perhaps some of the trouble with the intestines was also due to GvHD. To keep it under control, they have started administering corticosteroids, which gives a decent "boost."

The last few weeks have been emotionally and physically exhausting. Out of the 6 months that he has been fighting this battle, Peter has already spent over 3 of them living in isolation in a sterile hospital room, with no prospect of ever leading a "normal" life. It has been tough on Peter at times. But now he feels stronger, and the overwhelming feeling is: Hello world, I'm back and planning to stick around, so get used to it!

On November 10th, they had warned Peter that corticosteroids would disrupt his sleep. It gives you a boost, but it also takes its toll. But contrary to expectations, he slept very well. And he had another slice of bread with marmalade for breakfast. Funny, before Peter got sick, he couldn't stand sweet things. Desserts and cookies weren't his thing, so he always had savory toppings on his bread. The boosters are doing their job; he can stay out of bed all day. The blood count has also improved; the white blood cells are now at 2300 per ml. When they reach 4000, they start talking about "going home." The platelets are also higher than yesterday. These are all good signs. The red blood cells have decreased, but that seems normal since the new bone marrow will only produce them last. There will probably be an extra blood transfusion today or tomorrow. Hans comes in enthusiastically for the visit; today marks his eightieth back and forth trip. Peter's mood is now improving in leaps and bounds

November 11th: Today marks exactly five weeks since Peter has been in the sterile hospital room. The colors of the room are unpleasant - pastel yellow and harsh blue - but thankfully a few walls are left white. A stationary bike is available, but he hasn't been able to use it much. Despite this, his condition is improving. The morphine has stopped, and it feels like his brain has been cleansed with water. Finally, he has some clarity in his head and can think about life somewhat normally. In the morning, a team of four people comes to his bed for routine examinations. Often, a student is there who takes his blood pressure and listens to his lungs. Sometimes they also feel his organs (liver, spleen, etc.) to see if everything is okay. Some of these "kids" are so nervous that they have cold hands, which Peter finds amusing. He is happy to cooperate with them; after all, they are the specialists of the future! They make allusions that he may be able to go home soon, which is a comforting thought. In the afternoon, Etienne comes to visit. He is the hematologist who manages most of the contacts. Perhaps Peter can go home this coming Saturday. His white blood cell count is already at 5,300 per ml. He would then have to come back on Monday for a check-up and go home again for five days, if there are no complications.

November 10th: Peter wakes up with a strange feeling. It is a day with a normal hospital routine, but something is different. Maybe it's just guy talk, but his libido seems to be returning. After the first chemotherapy, it took a few months before he could get an erection again. Out of habit, he could still look at pictures or videos of handsome men, but nothing happened. Last night, he was in bed looking at handsome men on his tablet. It has its own internet connection since the hospital's internet connection does not allow access to erotic or pornographic websites. To his surprise, he got an erection! He can't do much with it at the moment since there is no privacy in the hospital; a nurse can come in at any moment, so masturbating is not an option. He feels like things are moving quickly at the moment. He's getting ideas about things he wants to do in the future. It's exciting, and it makes him pleasantly restless.

12 November: Fantastic news, Peter's white blood cell count is over 6000 per ml. So he can go home for the weekend! His platelet and red blood cell counts are also increasing every day. What a dream after more than a month in this sterile room in the hospital. He can hardly wait... The relief is immense: he feels good, happy, and strong. He feels like he doesn't have any problems anymore. He still has some high blood pressure and blood sugar, but according to the doctors, it's within limits and manageable. Wow, he's going back to the hospital on Monday for a day and a night, and then probably home for five days! Of course, it's too early to celebrate, but Peter is very hopeful; it finally seems like he's going to get better!

13 November: Peter wakes up in the middle of the night, he has no idea what time it is. He sees strange things in front of his eyes that don't disappear even when he blinks. They are glowing spots. He's sweating and feels like he's going to faint. This doesn't feel good. But how is this possible? He's terrified because he really wants to

go home tomorrow! It's not getting any better, and he decides to call the nurse. He can't speak properly. Fortunately, they quickly understand what's going on. His blood sugar level is too low. He's having a serious hypoglycemic episode. He eats cookies, drinks orange juice with sugar, and eats applesauce with sugar. After that, he feels a bit better. But it's not good enough; the doctors are working to find a way to get his sugar levels back to normal. They say it's one of the "things" we'll see more of in the coming weeks.

During the course of the day, the catheter is disconnected. During visiting hours, Hans and Peter receive instructions for their stay at home. They are given a huge list of "do’s and don'ts" regarding food, drink, hygiene, physical activity, and "range of action" (not further than an hour and a half's drive from the hospital!). Every disadvantage has its advantage: Peter is not allowed to involve himself in household chores or go shopping. Hans lovingly takes care of those. However, a second hypoglycemia during the afternoon makes it clear that adjustments still need to be made to the glucose management and insulin...

November 14th: Peter is indeed "on the road to recovery," but not completely there yet. He had hypoglycemia all night, with blood sugar levels way too low. It appears to be related to the medication, so the homecoming is delayed once again. The blood sugar level is consistently below the acceptable range (between 0.4 and 0.6) and it is sometimes quite a struggle to maintain it. It probably started when he stopped the artificial feeding. Many people then experience high values, which was also the case with Peter: 3 grams. So medication was given. However, his body apparently corrected itself much faster than usual, and the medication then had the opposite effect. For some reason, they continued with the medication until yesterday evening, and that's why it got out of hand. He had three severe hypoglycemic episodes on Friday, and it just wouldn't come up to par. He barely slept last night. In one night, Peter consumed more sugar than he normally would in half a year. He is now on a glucose drip again, and it seems to be stabilizing. Perhaps he can go home tomorrow after all.

Meanwhile, Peter turns on the TV and is confronted with the horrific news of the Paris attacks, leaving him with a heavy heart. Overwhelmed by the tragedy, he turns off all electronic devices and tries to process the information in his own way. He shares his deep sorrow with the nursing staff, who offer practical advice, "It's important for you to prepare to go home now."

Chapter 6

November 15, 2015: Peter's blood sugar levels are now within the normal range, so he can go home. Maybe just for a day. He packs his things together with Hans and then they're off! They stop by the nursing staff to say goodbye. He hardly recognizes anyone; they're not wearing masks! How strange. At half past nine, Peter shuffles towards the hospital exit. Hans can drive the car up to the entrance so he doesn't have to walk far outside. It feels strange to be outside again after forty days. The air moves differently, the sounds are very different. Wow, that car is driving fast, he thinks again! Peter has to close his eyes. The images flash by. After half an hour, he starts to get used to it again. After another half an hour, they finally arrive home. The dog is so happy; she doesn't know what to do. Peter, of course, has to be greeted and sniffed extensively. Friends from the village come to visit in the afternoon, they have a nice dinner together in the evening, and they chat and watch TV without any problems with blood sugar levels. Everything is actually going great, but he is so tired...

November 16: For the first time in a long time, Peter slept in his own bed. He wakes up feeling fresh and lively but soon discovers that he has almost no stamina. The toilet and the bedroom are on the 1st floor, which is 2x9 steps. Climbing the stairs is quite an undertaking! Going up is still okay, but going down is the most exhausting. He has to sit on the couch for ten minutes to recover. But maybe that's not so strange after all those chemos and forty days in the hospital. He thinks it's a good exercise and is overjoyed to be back home.

As agreed, they will return to the hospital at nine o'clock for the first "weekly" check-up. These check-ups may be necessary twice a week during the initial period, so there will be a lot of back-and-forth driving. The main thing is that the first night at home went smoothly. At the pharmacy, an enormous cardboard box full of medicines and devices awaits them: an insulin pen with accessories, daily pills and powders, drinks for everything and anything, it looks like a pharmaceutical factory! Now they just need to figure out what to take when and in what dosage. Peter takes the hospital transport (taxi) to the hospital, giving Hans the opportunity to give the house its daily cleaning. At the hospital, an IV is immediately inserted and the usual amount of blood is taken; about thirteen vials. It's the same routine; the doctors come by in the morning and afternoon, and blood pressure and temperature are measured a few times in between. This time, the professor also joins the medical team to see how things are going. He is the one who ultimately decided if the donor was suitable. Many factors must be considered to ensure that the stem cells are compatible.

Since the last chemotherapy treatment, Peter has had very little sense of taste. The taste has practically disappeared. He can still taste salt and sweet a little bit, but it gives food a very strange taste. Meat is a nightmare to eat; it's like chewing on wet cardboard. An orange doesn't taste like anything, literally; it's like biting into water. Peter can't imagine that this will last much longer. Desperately, he asks the professor if he thinks his taste will come back. "Yes, it will come back, but I can't tell you when," is his response. At half past four, they receive the news that all blood values are normal and that Peter can go home. Now they just need to wait for the taxi (with the customary French quarter-hour delay, of course). It will be 7:30 p.m. before he is finally home...

There are still 67 days left of the 100-day period.

November 17th: The night went well, but Peter was awake a lot due to the Prednisone. He went to bed at eleven o'clock, fell asleep at midnight, but woke up at three in the morning. The rest of the time he just dozed off. It doesn't bother him to stay awake for so long. Next to him, Hans is snoring contentedly. There are still many things to arrange during the day. Although Peter needs to take about 27 different pills (at various fixed times), they don't explain how to keep track of it all.

Some medications can only be obtained from the hospital pharmacy, which means yet another long trip. There is a lot more cleaning work than they had anticipated, so Hans has his work cut out for him. Despite everything, things are going well, although Peter's energy is only enough for ten steps at a time, up and down the stairs, after which he's already exhausted.

November 18th: After getting up and having a bite to eat, a bit of energy returns, but it's clear that even the slightest effort is quickly too much. They want to ask at the hospital next time: should they try to do as much as possible or avoid exertion? After the daily wash, Peter takes it easy again, sitting on the couch a lot and taking a nap in the afternoon. They're now about one-third of the way through the hundred days...

November 19th: The daily routine at a low-energy level is starting to become familiar. Today, Hans and Peter have to go back and forth to Besançon to have the CIP (the port for the infusion) removed. It will be done in the same private clinic where it was put in. The preparations and waiting time take quite a while. They don't have a bed and Peter sits the whole time on a kind of reclining chair. Eventually, he is wheeled into the operating room. The CIP will be removed by a plastic surgeon from Corsica who is doing a training program here. It takes much longer than he had expected and the anesthesia doesn't work very well. Oh well, he thinks, I've had worse. All in all, they come home late, and tomorrow is the next check-up day.

20 November: Up very early for the weekly check-up (6:45 am!), but Peter doesn't find it difficult. At the "hôpital du jour" (a kind of outpatient clinic with beds), they examine all measured values: blood values, blood sugar, bone marrow, oxygen, in short, "the works." The bone marrow puncture goes as usual without any problems. They numb the skin and the piece of the sternum they will drill through. Then they push a large, thick needle with a lot of force through the sternum. The bone marrow is then aspirated. It looks a bit like thick, greasy blood. Peter hardly feels the procedure; it only gives a pulling feeling for a moment. Peter is surprised every time because he hears stories from other people that they would prefer to be under sedation for such a procedure. The results turn out to be all in order, and by one o'clock, he is already in a taxi home. He had expected to be finished at the end of the day. So far, the process is going entirely according to the forecasts, except for one small virus that showed up in the blood tests. So tomorrow, he is off to the pharmacy for the 28th medicine.

21 November: The insulin pen has to be replaced with pills. Peter has a bit of diabetes, which is probably caused by the corticosteroids. It was also discovered yesterday that he has a Cytomegalovirus. The medication they give for it is quite expensive: three thousand euros for a jar for a month. He cannot imagine how much his treatment has cost so far. You could probably buy a nice little house for that amount. Peter is happy to be back home with his beloved Hans. As a caregiver, Hans also has a considerable burden. They are looking for some support because Peter really cannot do anything in the house himself. They are glad that winter is beginning because in the summer, there are many insects that also come inside the house. But now, there are no flies or mosquitoes inside. Outside, it has really become cold, and they spend the day by the fireplace. Next Friday, there will be another admission to the hôpital du jour, and then probably just a consultation.

A new problem arises in the following days. Peter is sleeping reasonably well and his blood sugar levels are good, but he quickly becomes short of breath. Even with a small amount of exertion, he begins to pant. As the weekend passes, he begins to feel worse and decides to stay in bed. In the afternoon, they call the hospital for advice. After some consultation, they are told that Peter needs to go to the hospital for a lung scan the following day. This will mean yet another trip to Besançon. They review all the drug information leaflets again, and one of them lists shortness of breath as a possible side effect. They are glad that they didn't throw away the leaflets as one of the hematologists had recommended. It has been 40 days since the transplant, so they are approaching the halfway point of the "dangerous period". It remains a very tense time. At the hospital, they examine Peter's heart, breathing, blood, and oxygen levels, but find no specific problems. The lung scan is postponed until the day of his weekly check-up, which is next Friday. With a few breathing exercises, Peter's energy improves considerably. This gives him a little more freedom to move around and do things. It is simply a matter of taking a few deep breaths before exerting himself.

On November 26th, Peter wakes up in the middle of the night with sore knees. It is a strange, stabbing pain that he cannot relieve. Standing up next to the bed doesn't help either. He has no idea what to think. An hour later, his wrists and index finger joints also begin to ache. Resting in bed does not seem to alleviate the pain, so he decides to get up and make breakfast. As usual, he checks his blood sugar level with a finger prick test, and it is low again. Not dangerously low, but still low. He decides to have a sweet breakfast, with lots of jam on his bread.

He didn't read all the leaflets of his medications, which only makes you sicker. He also can't remember if joint pain was listed as a side effect of any of the medications. Tomorrow, he has another check-up at the hospital, so he can ask the hematologist about it. Peter and Hans have come a long way; they no longer call the hospital for every little thing.

November 27th: the day starts off poorly; the taxi is three-quarters of an hour late. The driver hadn't checked where he needed to pick up the patient the night before. Contrary to his usual behavior, he grumbled at the man. Today is a day of check-ups at the "hôpital du jour." Upon arrival, a room is assigned where the patient stays for the rest of the day for tests. First, the IV is connected, then the first blood draw. The nursing staff is very kind; they remember Peter from when he was in the "intensive care" ward. The hematologist stops by for a quick check-up; listens and knocks, takes temperature and blood pressure. The standard routine. Peter mentions the pain in his knees and joints. It turns out to be a side effect of reducing Prednisone. And that seems to be true: earlier this week, according to the hematologist, he could reduce his dose by half. The message is that these side effects only last a short time.

It's good that they have a television in the room, and Peter has his tablet with him. It's quite boring, and not much else is happening. Around noon, he hears that all his blood levels are fine, and he can go home at 1 pm. There was a mild GvH, which has reduced the risk of recurrence. The nursing staff calls for a taxi so Peter can leave at 1 pm. But unfortunately, at two o'clock, there still hasn't been a taxi. He doesn't understand; upon inquiry, the nurse insists that she really did call for the taxi. Now he calls 62even himself. The taxi company knows nothing, grrrr. Anyway, he is picked up at three o'clock and can finally go home. In France, the word for patience is equivalent to "patient" for a reason. When he gets home, Peter still feels good and has a lot of energy; a good reason to visit friends in the village for a little distraction after such a day.

As the end of the month approaches, Peter's condition is gradually improving. Although he still finds it challenging to climb two sets of nine stairs to use the toilet, he can now walk around indoors without getting too out of breath. Peter is grateful that he has not fallen and can now do small tasks like closing the curtains or putting a pot on the stove without feeling too overwhelmed. These small steps towards independence are significant for him. This week, Peter and Hans plan to visit their friends Dominique and Isabelle in the village for two hours before returning home for Peter to rest.

On November 30th, the district nurse came to remove the stitches and take blood. However, removing the stitches was difficult because some of them were under the scar tissue. She couldn't remove all of them, so they'll have to check again at the hospital next time.

Later that day, Étienne, Peter's hematologist, called to inform him that his creatinine levels are much too high. He urgently needs to drink two to three liters of water every day. Although Peter feels annoyed at the inconvenience, he understands that he needs to follow the advice to improve his condition.

December 3rd: the past few days have been quiet for Peter and Hans, who took a pleasure ride in the car. Peter hasn't ventured outside much, as there are still too many risks of virus infections in certain areas. His lack of energy is still unbelievable. He tried to walk the dog, but the 30-meter distance from the garden gate to the house, which also rises half a meter, is nearly insurmountable. Once inside, he needs to rest on the couch for half an hour. It takes considerable effort to not become discouraged by this. Today marks 50 days since the stem cell transplant: exactly halfway through the "high risk" period characterized by the hematologists! The high-risk period refers to two dangers: rejection (both by the patient's body of the transplant and vice versa) and infection (with a fungus, microbe, bacteria, or virus, in increasing order of danger). Fortunately, they live fairly isolated on the Domaine du Bac. There are few sources of infection or flu epidemics here. The rest of the week passes without any noteworthy events. A check-up at the hospital shows that everything is in order, and the creatinine level is back to normal as well. A minor adjustment to the medication and they continue forward. Peter has some red patches on his skin (a GVHD), but they are not getting out of hand. He tries to do exercises regularly, such as walking the dog, climbing stairs, and rowing on the rowing machine, and it pays off! He can gradually do more and more, and by the end of the week, he can walk the dog three times a day without interruption! It may not seem like much, but for Peter, these are victories of almost Olympic proportions.

On December 7th, early in the morning, the district nurse comes to take Peter's blood. It's still dark outside when she arrives at the door, but it's good that she comes so early because Peter needs to be fasting when the blood is taken. At half past eight, the alarm on his phone goes off, reminding him to take his Neoral medication. After taking his medication and having breakfast, Peter feels tired and shivery. He doesn't have a fever, but he doesn't feel great. He decides to go back to bed. Around lunchtime, he gets up and has lunch with Hans. Peter is feeling much better and decides to go for a walk outside. The sun is shining brightly and the path along the river looks beautiful. The distance from the garden gate to the village border is exactly 500 meters. He decides to do his best. His step counter shows that he has walked 400 meters. But he still has to walk back. He brings his phone with him just in case he can't make it. Standing still to rest doesn't help because standing up straight is just as tiring as walking. So at this point, he turns around and starts walking back. It seems to be going well. Meter by meter, the garden gate gets closer, and he thinks he can make it. But then at the garden gate...the ground slopes up again, and he can't make it. Fortunately, Hans is waiting for him and gives him an arm to support him for the last few meters. He quickly goes to bed and sleeps for an hour. He wakes up to the phone ringing. It's the hematologist calling to say that his blood values are very good and that the next appointment will be shortened to just an hour. Things are heading in the right direction.

On December 8th, intense emotions overwhelm Peter as memories of pain and difficult moments resurface. Hans and Peter sit together crying and laughing about everything that has happened. Peter once wrote to friends: "Dying doesn't seem bad to me, but the road to it scares me terribly." That's still true, although now the hope of survival predominates. He has a philosophical thought about it: everyone supports you in getting better and surviving, and that's why he feels connected. But dying is something you really do alone. The most beautiful image he saw of that was when he was twenty in Rome. There, Peter saw the sculpture of the dying Gaul, originally sculpted by a Greek. It moved him deeply. The rest of the day, they are busy preparing for Hans' trip to Haarlem (packing, stocking up on supplies, gathering documents). A lot of administrative things need to be taken care of with the accountant.

9th December: Hans leaves for the Netherlands at quarter past seven. For the first time since April, Peter is on his own, but Isabelle and Dominique will come over to make dinner and eat with him in the afternoon and evening. The day goes well, and even walking the dog isn't too tiring.

10th December: Peter enjoys his newfound independence to the fullest. However, it does put him to the test. He can take care of himself for most of the day, making tea, preparing and eating breakfast, walking the dog and even taking an extra walk. In the afternoon, his friends from the village, Isabelle and Dominique, come over to help with cleaning, shopping, and cooking. It's all so exhausting that he sleeps longer that night - 6 hours instead of the usual 4.

14th December: Peter's condition seems to be improving rapidly. Perhaps it has to do with the reduction of certain medications. Today, he walked over a kilometer with the dog at a fairly normal pace and can climb the stairs in the house without being out of breath. The prednisone has been reduced from 80mg to 30mg per day. Now we have to wait and see if his extremely swollen face will return to more normal proportions.

Fortunately, he is also sleeping longer at night and falling asleep on the couch late at night - something he hasn't done in a while! The skin on his chest and back is a little red, which pleased the hematologist to see, as it seems to indicate that a mild GVH is doing its job. Peter is now 39 days away from the end of the 100-day period, and there have been no complications so far! At his last hospital checkup, he was warned about the flu epidemic. He needs to be extra careful with people who visit, or wear a mask.

19 December: Some things are more tiring for Peter than others. Walking one and a half kilometers with the dog goes well, while taking a shower is super exhausting. Yesterday, all values were found to be in order during the weekly checkups, and once again the dosage of some medications, including Prednisone, was reduced, which in turn affects his energy levels. Peter wonders if he is allowed to drive, it is not prohibited but it greatly depends on whether he feels fit enough.

22 December: Peter wakes up feeling a bit groggy and sweating. He doesn't feel well at all. As he does every morning, he takes his temperature and checks his blood sugar levels by pricking his fingers. Almost 38 degrees, which is quite high for early in the morning. He gets scared and stays in bed. Fortunately, a few hours later, the temperature returns to normal. Due to the Christmas week, the hospital day is now on Tuesday instead of Friday. The day marking the end of the dangerous period is now less than a month away, but the occasional

minor setbacks still keep Hans and Peter on alert. The myelogram (the bone marrow puncture) turned out to be good and all other values were excellent as well. They still need to be very alert to symptoms of any possible GvH...

The rest of the week goes by calmly and on Wednesday, Hans and Peter eat in a restaurant for the first time in three months. They rest well beforehand and see if Peter can manage it. It goes well and on Thursday, they eat with friends in the village. Hans and Peter traditionally spend Christmas at home and enjoy mashed potatoes with meatballs. Peter eats for the company and because he has to, but there is no taste to it.

On December 27th, today the day counter reaches 25; three-quarters of the dangerous period has passed. Actually, there have been no noteworthy complications. Occasionally, there's a slight fever and sometimes some red spots on the skin. The intestines are very irritated; Peter pays the price for eating anything with spices. But without spices, the food tastes bland, so it's hard to find a middle ground. Due to the lack of taste, he has to make an effort to consume enough calories. He eats cookies excessively. While he doesn't normally like sweet things, let alone cookies, now they can't keep him away from them. The problem with his intestines is quite troublesome. They have a change of clothes ready in the car because sometimes Peter has a hard time holding it in.

The next morning, Hans and Peter go to Gray to do some shopping. They want to buy some extra lamps and browse around a furniture store. It's a pretty big store, but there are benches and chairs placed at regular intervals so Peter can sit down occasionally. He feels a slight urge coming on, and he knows he needs to hurry. He walks more carefully and feels the pressure increasing. This is not going well; it's going to be a mess. Suddenly, he sees a door with "toilet" on it. He has to make an effort not to rush, or it will definitely go wrong. Once on the toilet, it's like a liquid manure cannon. But luckily, he doesn't need to change his clothes.

Normally, Friday is the day to go to the hospital, but due to the holidays, everything shifts. This time Wednesday is the "hospital day." Peter already noticed that he was getting weaker in the past few days and that the palms of his hands were turning pale blue. He has all the symptoms of anemia; poor condition, headaches, ringing in the ears, and despite a thick sweater, he feels cold. This means a blood transfusion; the red blood cells are replenished. This makes the visit to the hospital take longer. They suspect that his intestines are upset due to a moderate "graft-versus-host" reaction, so the dose of cyclosporine is increased again.

Finding a balance with the medication remains a challenge. There is, however, another good result; the "chimerism test" shows that the blood is now 100% derived from the new stem cells. The sun is shining, and it looks cheerful outside. Especially now that the leaves have fallen, you have beautiful views. Walking isn't easy, but Hans and Peter go out in the car almost every day.

31 December: With the extra dose of red blood cells, the amount of available energy noticeably increases: less difficulty with the stairs and longer endurance. Tonight, New Year's Eve, Hans and Peter are spending time with Isabelle and Dominique. They invited friends from a bed and breakfast a few villages away. A half glass of champagne is enough for Peter because any more than that will cause his medication to protest. The evening is long, but he tries to endure it. With great pleasure and a few tears, midnight strikes. Hans and Peter go home at half past one, exhausted but satisfied. Another hurdle has been overcome.

The next day, Peter pays the price for his night out. He sleeps in, but remains groggy all day. Hans doesn't rely on Peter too much. However, the last three weeks of the dangerous period have now arrived. On January 21, the hundred-day period will be over.

On January 5, 2016, Peter celebrates his 59th birthday. It's quite an accomplishment after being diagnosed with CMML. It didn't look so promising a while back. He had a blood transfusion last week, and it did him a lot of good. He now has a lot of energy and is less out of breath. Tomorrow, Peter will start with EPO, but it seems to work a bit slower. It's a countdown; he has about 19 more days left in the 100-day period after the allogeneic stem cell transplant, which he has so far managed without complications. Fingers crossed for the follow-up. Peter has undergone a shocking transformation in appearance; from a middle-aged man with a paunch and a narrow face to a man with a paunch, little muscle mass, and an incredibly bloated face without hair. Hopefully, he will regain his hair, and the prednisone can be stopped at some point. But even if that doesn't happen, it's better than being dead.

January 8th: Another milestone; for the first time, there is no weekly hospital visit. Peter only needs to go for a check-up next Monday. He is able to drive short distances again. As things improve, his impatience grows; the recovery seems slow. And then there are the discomforts: unable to eat anything without tearing up, and no taste either. Peeing very frequently, irritated skin, and shortness of breath. At a wrong moment, Peter quickly stands up from the couch and everything turns black before his eyes. He literally can't see anything. Panic sets in; "What is happening now?!" He quickly sits down again and slowly his vision returns.

January 11th: This morning, Peter went to the hospital for a check-up again. We are approaching the end of the risky 100-day period, and he was curious about what will change now. First of all, over the next few weeks, the medication will be gradually reduced. Also, the frequency of check-ups will decrease from once a week to once every 2-3 weeks. Furthermore, the doctor expects that with the reduction of Neoral (a medication that prevents rejection) and prednisone, Peter's energy levels will improve significantly. According to the doctor, everything is going fantastically. No major complications have occurred over the past few months, and Peter has not developed any infections.

After next week, he won't have to wear a mask anymore (in the hospital and in crowded places such as supermarkets), and he can move around more freely. This means that Hans and Peter can go on city trips again to escape the boredom here. As long as there is a nurse station nearby where blood can be drawn, it's all good. In case of a complication, they need to be able to return reasonably quickly. Due to the chemotherapy, Peter had quite a few dark pigmentation spots on his body, and they are now starting to disappear. Another good sign. His hair and taste are still not great, but these are minor issues. Peter is a bit overwhelmed, but he's doing as well as he can.

January 21st: today is the last day of the 100-day period! Peter has made it through without too many complications. In fact, until last weekend, he had no major issues except for the difficulty of rebuilding his strength, which is still progressing very slowly.

But over the weekend, his intestines started to act up, which eventually led to diarrhea, and on Monday morning he suddenly had a fever of 38.7 degrees. He immediately called his hematologist, who advised him to start taking Augmentin (antibiotics) and a paracetamol. He had an appointment for a check-up at the hospital that afternoon, and since the fever had already subsided, the appointment could proceed as planned.

Now that the first hundred days are over, it also means that the first vaccinations (DTP) can be given. Later this year, this will be repeated, and a flu shot and a pneumococcal vaccination will also follow. Another bone marrow biopsy was taken this afternoon. Again on the breastbone, and again Peter had no trouble with it.

The hematologist believes that the diarrhea is the result of mild graft-versus- host disease affecting the intestines. It is expected to resolve itself in due time. The frequency of check-ups is being reduced to once every three weeks, which is wonderful and provides more room to do other things.

Chapter 7

February 4, 2016: This week Peter received the results of his chimerism test. There is no trace of faulty cells and his blood is 100% from the donor. During his last visit to the hematologist, he received a lovely card from the donor expressing her hope that Peter and his family are doing well, and she would love to hear from him again. What's remarkable is that she is a French speaker, but bought a card with Dutch texts on the front. He intends to reply to her message as soon as possible.

It's now 3.5 months after the stem cell transplant, and for a few weeks now, his hair has started to grow back. At first, it was hesitant, only growing on his upper lip. During the first few months, except for his eyebrows and eyelashes, Peter was almost completely bald over almost his entire body. This saved him a lot of razor blades; before the illness, he had to shave almost twice a day if he wanted to be completely smooth. After the upper lip, the area under his lower lip and cheeks were next. The hair there is now growing thickly. And now on top of his head too! Not on the sides, but on top. It looks funny, those dark stubbly hairs. A year ago, he still had a thick head of gray hair. He has no problem with being bald or his hair growing back now. What he finds much more difficult is his sense of taste. It is still not normal, and Peter must often ask Hans to taste the food first because he can only rely on his routine when cooking. His sense of smell is good, but that often leads to confusing experiences: he can smell a good glass of wine and like it, but when he tries to taste a small sip, the taste palette is completely off. It's like a delicious tomato sauce suddenly tastes like chocolate spread. He has good hope that as his hair (the cells with fast division) grow back, his sense of taste will also normalize.

Peter is striving to lead a more "normal" life by doing his own shopping and making appointments, organizing outings for visitors and guests, and trying to relieve Hans of many of the daily tasks. It can be physically demanding at times, but he realizes it's quite "self-reinforcing" mentally. It's a movement away from death instead of towards it, and that feels good!

On February 8th, Peter had another check-up at CHU Minjoz Besançon. Hans came along this time, which led to some funny situations. While waiting in the hallway to check-in, a specialist who monitored Peter during the "sterile" period walked by. Peter has a very thick "prednisone head," but

Hans looks normal, of course. The doctor didn't recognize Peter at first, but when he saw Hans, it clicked.

Fortunately, there are some changes regarding medication now: the cortisone will be reduced from 15mg per day to 5mg. The Rovalcyte, Noxafil, Retracit (EPO), and Baraclude will stop (once they run out). Peter hopes that this will go so well that the cyclosporine (Neoral, currently 75mg per day) can also be reduced.

Furthermore, physical changes continue: Peter sees his legs becoming stronger again, the muscles in his arms are getting stronger too (probably due to lifting heavy pans in the kitchen). The last dark pigment spots from the chemos are also starting to disappear. Another significant change is that he can exhaust himself quite a bit now, but after a good night's sleep, he fully recovers. He still has some digestion issues, but this greatly nourishes his optimism.

March 4th, 2016: Peter's taste has returned! Friday's bulletin:

> *"Fortunately, things are still going very well. Peter isn't where he wants to be yet, but he's*

still taking a step forward every day. The downsides: his muscles are still very weak. When he's on his knees to pick something up, he has a lot of difficulty getting back up. Recently, he stumbled on the grass in the garden and had to take some time to put all his parts back in place ;-). He also has a mild case of GvHD or Graft versus Host disease, which is when the donor material is fighting his body. It's been identified in his intestines, and he has to go to the bathroom about 10 times a day. However, this has improved with adjusted medication. The good news is that he has regained his sense of taste! Yesterday, they went to a nice restaurant (De Cactus), and it suddenly dawned on Peter. He's also taking fewer and partly different medications since last week. He's not sure if it's because of that, but he's very happy about it! The frequency of his check-ups has also been reduced, and he's received his first vaccinations. It's also positive that his hematologist calls him an "exemplary patient." He has had no significant complications after the stem cell transplant, and what's also exceptional is that he hasn't been readmitted to the hospital so far."

He doesn't know if he should consider it a positive thing (he found it easier without it), but the hair growth is back. There's a downy patch on his head again, and the first signs of pubic hair are appearing on the rest of his body. He also has to shave almost every day again. They're feeling very positive and are happy that not everything is about that horrible disease anymore. They can read books again and occasionally get bored with the gloomy weather (what a luxury!). Now they're considering some more distant vacation destinations; they'll be puzzling over fun destinations in the coming months.

On August 7, 2016, half a year later, Peter is sitting in the shade of his house in the French countryside, about an hour's drive from Dijon. It's around 24 degrees Celsius in the shade, couldn't be better. It's exactly 10 months today since he received his allogeneic stem cell transplant. He's making great progress, the day before yesterday he took a brisk five-kilometer walk on flat terrain, and this morning he walked three kilometers on difficult terrain with lots of climbing and descending. He's not even tired! And to his great delight, his sense of smell and taste are getting better and better. His face is also starting to return to its normal proportions: he's almost got his old narrow wrinkled mouth back. Apparently, hydrocortisone doesn't make you so bloated (2 mg per day). In addition to that, he only takes some vitamins, Valaciclovir, and Prograf (1.5 mg per day). The latter will be reduced again this month. The blood counts are a bit variable (especially the neutrophils). What a contrast to the ordeal Hans and Peter have been through. Occasionally, they still think back to it with tears in their eyes. And of course, it can still go wrong again, but Peter simply doesn't believe in that anymore. He's even starting to consider picking up some (volunteer) work again. Anyway, "la vie est belle!"

On October 7, 2016, Hans and Peter are on a small trip in central France. According to the plan, they'll be back home in Ray-sur-Saône on Sunday. They're having a fantastic time; it's almost like old times when Hans and Peter used to travel around France a lot. The complaints resulting from chronic GvHD have become a bit less, at least Peter has the energy to do things again. Tonight was a real celebration. Peter previously described how losing his sense of taste and smell was very difficult for him. Now it's back! He enjoyed a few glasses of his favorite red wine, Saint-Emilion, immensely.

March 15, 2017: Another six months have passed, and everything is going very well. These early spring days are delightful in Northeast France. Today, the temperature is 18 degrees, and tomorrow it is predicted to be even warmer. Peter is now able to do a lot of work in the garden, and despite the difficult task of removing the overgrown ivy from the gravel path, he persists and makes good progress. He spends thirty-five minutes on the rowing machine, pushing himself to the heaviest level, to maintain his fitness.

In a charming anecdote, Peter reminisces about the day he met Hans 36 years ago in an Amsterdam café. As a student, Peter used to cut hair to make some extra money, and upon seeing Hans with long hair, he offered to give him a trim. Much to Hans's surprise, Peter took out his scissors and cut his hair on the spot. Ever since then, Hans has never gone to a hairdresser, and Peter continues to give him haircuts to this day.

That evening, they enjoy a delicious vegetarian Indian meal, which Peter prepares as usual. Peter is happy to be able to cook and take care of himself again.

April 20, 2017: Today is a special day for Peter as he receives a response from the stem cell donor he had written a thank-you note to after celebrating a holiday in Portugal. The donor, who writes in Flemish, expresses her appreciation for Peter's photo of a beautiful spot in Porto and shares a stunning photo of the parliament buildings in Budapest, revealing that she too loves to travel. Peter is touched by her response and grateful for the opportunity to connect with her. She ended her message with "from a young twenty-something to a sprightly sixty-something". That brought a very broad smile to Peter's face!

July: things are still going very well. In 1996, Peter quit smoking after he suffered a collapsed lung in May of that year. At the time, he smoked a pack of tobacco per day! Naturally, he suffered from it; he had long-term coughing at night and frequent problems with his lungs. After the collapsed lung, it was very easy for him to quit smoking. And after a month, he felt great! Full of energy.

Now, Peter tells friends that he feels the same after the stem cell transplant as he did then: a forty-something who quit smoking. He remembers that feeling like it was yesterday. It's as if the clock has been turned back twenty years. In several ways: after the chemotherapy, his libido disappeared. His sex life had not been great long before the cmml diagnosis was made. When he was in his forties, Peter had adventures that went beyond the beaten path. Fortunately, Hans was never jealous, because that's how they eventually got to know each other. A few weeks ago, Hans and Peter went on vacation to Italy (Tuscany) and there he rediscovered the game of men hunting on the beach of Marina di Torre del Lago (together with Hans). It was a revelation for Peter! Finally, he can do it again. He felt so insecure about his body for so long. And now it's all about fun again.

And then there's working in the garden; he can handle everything, carrying stones and sawn branches. Weeding and mowing the lawn. But this afternoon, the biggest surprise came for Peter: he walked down the path to take the dog for a walk, and suddenly he felt like running. Tribord, the dog, looked at him in surprise and ran along for a bit. 50 meters of running; wow! He promises himself to do 100 meters tomorrow! It will be 2 years in October since he received the allogeneic stem cell transplant. Peter is not yet out of the danger zone, but he feels like he is. In early September, he will talk to people who want to set up a patient association in France for those who have undergone a stem cell transplant. It doesn't exist here (yet).

August 8, 2017: For the past three days, Peter has been crying at the slightest thing. Sometimes from joy, other times from fear, but mostly from the memories of the horrors he endured. Yesterday, he had his quarterly check-up and they naturally had to take blood. This morning he found out that all his values are very good. Immediately after his stem cell transplant, he kept a close eye on his blood values down to two decimal points. Now, Peter is satisfied if the hematologist says it's okay. The blood was taken yesterday by a nurse who also works in the hematology intensive care unit. She remembers Peter well from the time he was in "isolation" there. She was very happy to see how well he's doing. He told her that he's been struggling mentally in the past few days and that the memory of the isolation is very emotional for him.

She immediately asked what they as nurses can do to alleviate/improve that period for patients. Peter immediately burst into tears again. At that moment, Professor DeConinck (head of the department) walked in. He saw that Peter was in "good hands" with the nurse, gave him a warm look of recognition, and left quietly. The memories of the days after the stem cell transplant still grip him by the throat. After months of preparation with grueling chemotherapies, not knowing if it would ever get better. For weeks, he was in a sterile room where he only saw people with masks on their faces and caps on their hair. He was touched with latex gloves. "Will I ever be able to lead a normal life again?" was the big fear. Brrr, just thinking about it now...

But the good news: the dosage of Jakavi is halved! He can probably stop taking it in October. Hans and Peter want to go on holiday to Vietnam in December. Peter is working on new projects again to make the best use of his time. In other words: things are going really well. It took a while, but it was worth it; a new life.

Epilogue:

Through trials and tribulations, they have attempted to document the progression of the disease. It seemed fitting to end the story with the trip to Portugal (in December 2016) when Peter was able to run up the stairs for the first time in a long while.

But the story never truly ends. Hans and Peter continue to carry it with them. Whenever Peter thinks back to it, he realizes that the experience did not enrich him. Instead, he has become afraid, afraid of death. He has lost his innocence and naivety. He can no longer think that death is not a serious matter. And yet, he has gained an experience. In hindsight,

Peter identified May 5, 2015 as the day his world fell apart, when his fears became reality. But in reality, he had not been feeling his best for years. Sometimes, it felt as if he was wading through molasses whenever he tried to speed up his pace. He struggled to swim 30 meters, whereas he used to be able to swim great distances. They called it a lack of fitness, not enough exercise. But perhaps it was the other way around; he moved so little because his fitness was so poor. And that may have had a cause. Leukemia was likely present chronically for years, and during that time, he learned to live with its symptoms. He had some ache or pain every day. That was also normal. Colds never lasted shortly, and his skin protested at the slightest bit of stress (psoriasis). He will likely never know whether these were all warning signs. But now, almost all of these discomforts have disappeared.

The changes in Peter's life are more profound than just his physical functioning. They are not limited to that. Peter was known for his worrisome nature, always searching for "the meaning of life," and plagued by regular winter depressions. Leukemia and the difficult healing process and long period of recovery have made it clear to him that one does not have the luxury of wasting time on life questions that only make life more difficult. In the past, when he experienced an attack of melancholy, he would just sit with it until it passed. Now he realizes in a split second that there is no room for it; it is a useless use of time. That discipline is good for his mental health. Does that mean that he has now discovered the meaning of life? Probably not, he has discovered that he has a sense of purpose in life. The danger has not yet passed. The risks are much lower, but they have not disappeared. The statistics are clear on that. Fortunately, this realization fades into the background.