

Dorien's New Liver



Barbara

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This booklet is a preparatory book for children who need to undergo a liver transplant. It has been translated from my original Dutch book which was published in 1996 by Beatrix Kinderkliniek, AZG, Groningen, The Netherlands.

This book is not autobiographic. Dorien, the fictitious patient, lives in Holland. In this book we accompany her on her long way from pain to transplantation.

You, together with Dorien, will get to know exactly what

happens when your liver is so sick that you have to have a new one. You then have to undergo a big operation. But before that occurs, a lot of things will happen. And after that too.

Experience this adventure with Dorien.

I would like to thank some people.:

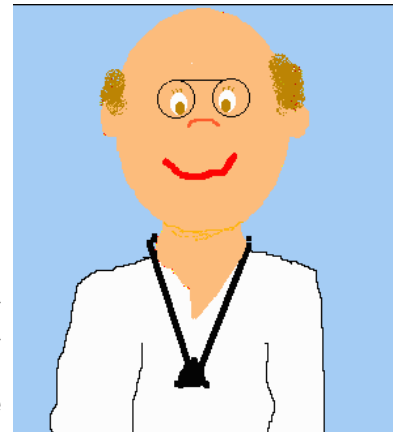
- all nursing staff at the "Beatrix Kinderkliniek" and at the intensive care units who have cared for me
- the team of liver-transplant specialists of the A.Z.G. (Academisch Ziekenhuis in Groningen)
- all doctors who did their best to get me back on the track
- Sippy ten Brink who had the idea for this book and whose support and inspiration helped me along
- all good friends in Graz (Austria) who helped with the German translation
- all good friends in Tasmania (Australia) who helped with the English translation.

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For a little while now Dorien has not felt well. She has a stomach ache. She visits her local doctor. He says that he doesn't really know where the pain comes from; so he sends her to the hospital in her local town.

At the hospital Dorien and her parents are met by a nurse. She says, "Go into the Examination Room. The doctor will be along soon."

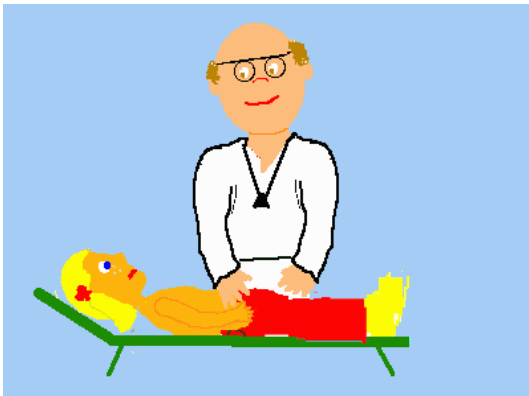


In a little while the doctor arrives.

This is a doctor who knows everything about tummies (a *gastro-enterologist*). He asks Dorien how long she has had a stomach ache and where exactly the ache is.

He listens to her stomach with a *stethoscope* and he examines her. Then he presses on Dorien's tummy.

Dorien has to say when it hurts.

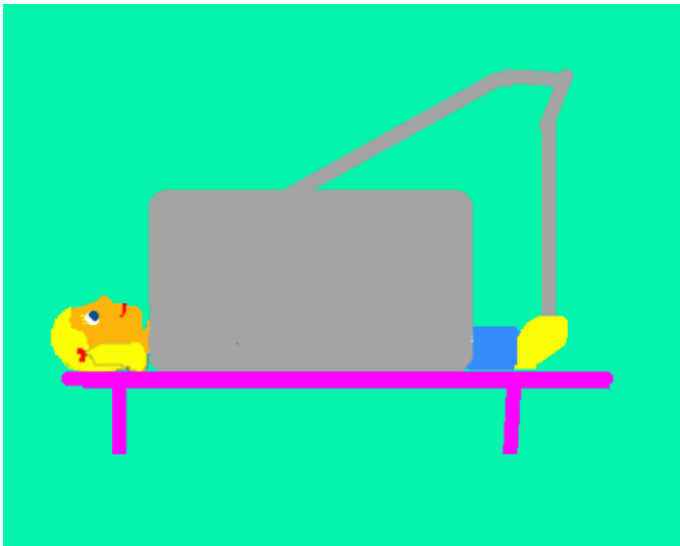


Dorien's liver is being examined with an ultra-sound sensor. For this the doctor puts some cold jelly on her stomach. . Then he moves the sensor across her belly. This tickles a little bit - Dorien laughs.

The doctor watches the monitor. Dorien can only see grey, shapeless things on the screen with here and there a coloured spot.

The doctor sees that Dorien looks puzzled and he explains: "I can see your inner organs on the screen. This here is your liver." Dorien can still not make sense of the fuzzy picture on the screen. At least, the test does not hurt. Finally, the doctor is finished and he wipes off the jelly.





After that Dorien is taken for a scan. This is also a photo of the inside of your body. The machine that does the scan looks a bit like a tunnel. You have to lie in the tunnel. Then the photo is made.

They also do a blood test.

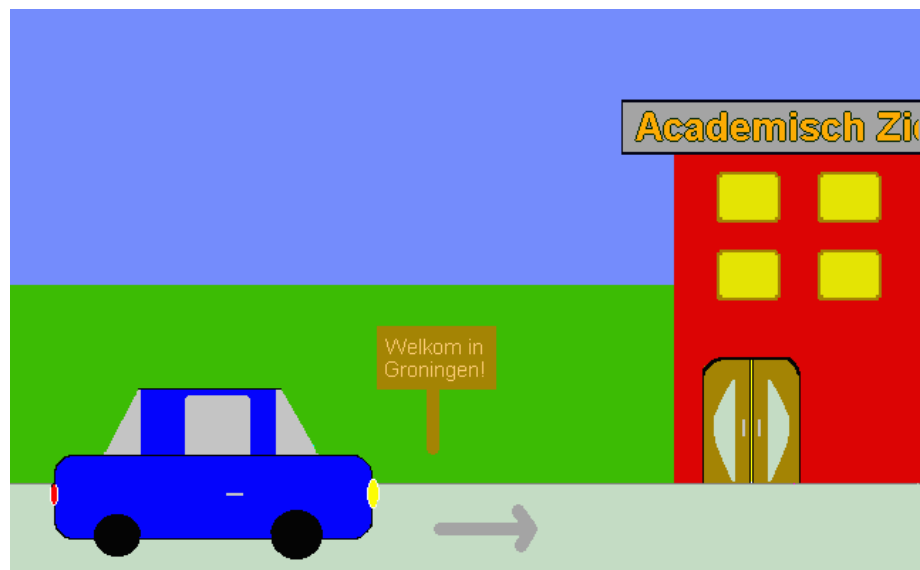
After all that Dorien and her parents go to the waiting room to wait for all the results. Here comes the doctor. He takes Dorien and her parents to a little room. There he tells them that Dorien's liver is sick. So sick that it is quite possible that Dorien will need another liver. People call that a donor-liver. He says, "I will ring a doctor

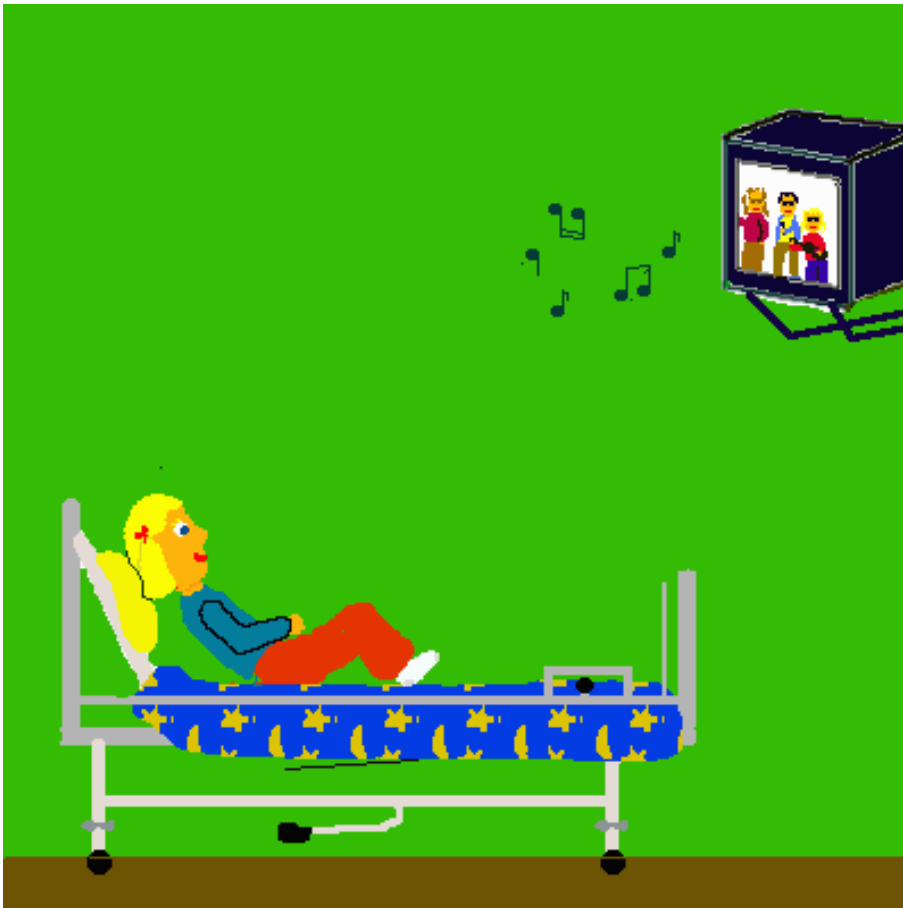
in the A.Z.G, the Academic Hospital in Groningen. That is the only hospital in the Netherlands where they do liver transplants on children. They have a lot of knowledge about diseased livers and I am sure they can help you.

They will do various tests to find out exactly what is wrong with your liver, because they want to know if you really need a new liver. Sometimes a transplant is not necessary, and they might be able to cure the disease with some medicine."

So, a few days later, they drive to Groningen.

In the A.Z.G. they go to the Beatrix Children's Clinic where they see more new faces. Here they also have a gastro-enterologist. His name is Dr Byleveld.





Dorien gets a bed in the children's ward called M2. She has a room with a telephone, radio and even a T.V.

'Wow! That's cool!' Dorien thinks.

Already on the first day Dorien meets a lot of nurses and staff and she is allowed to call them by their first names. All the doctors and nurses have a 'beeper' (pager) and all the patients, and Dorien too, have a bell in their rooms. If they have a problem they simply press the bell. The bell activates the 'beeper' and then the nurse comes to see what is the matter.

Dorien has eight nurses who look after her.

Here they are:



The nurses change three times a day. Then the 'old' tired nurses go home and the new 'fit' ones take their place. Of course the nurses work all night, too.

Today Anne is looking after her. She is taking Dorien's blood pressure and temperature. That will happen at regular intervals - luckily it does not hurt.

"Do you perhaps know a place where my wife and I can stay while Dorien is in this hospital", asks Dorien's father. "We live quite a distance from Groningen and we will not be able to go up and down each day."

"Yes of course", says Anne. "Here there is a special house for the parents; it is called The Ronald McDonald House.

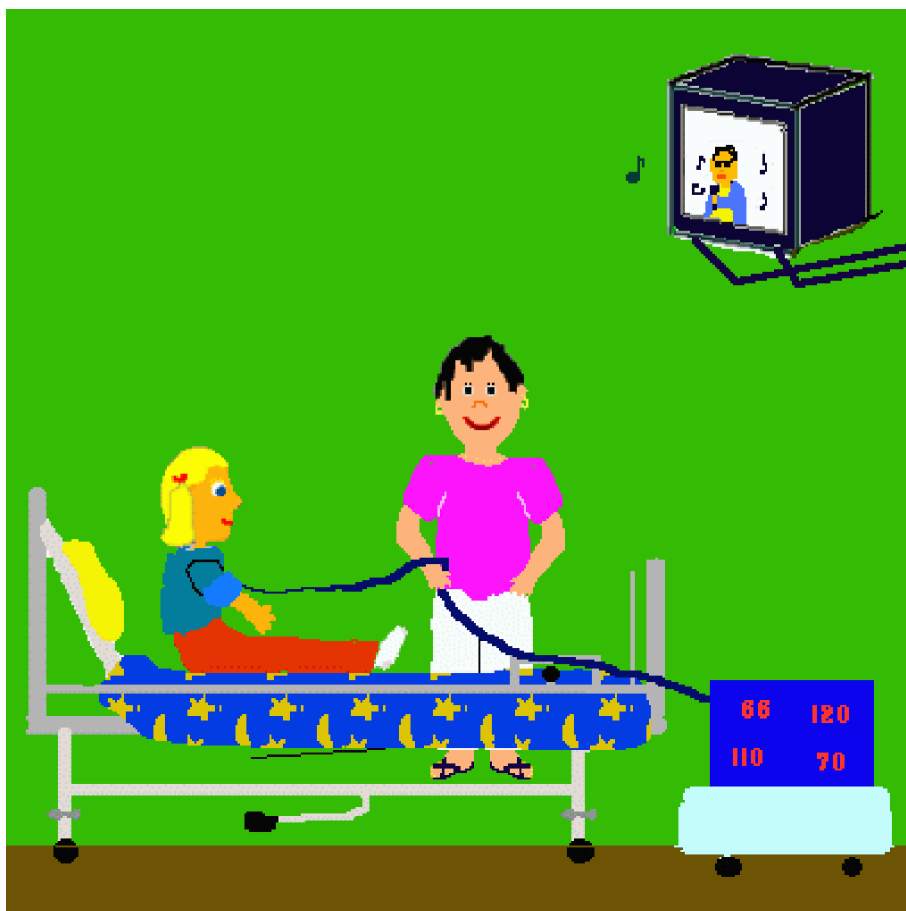
This house is close to the children's ward and parents can stay there while their children are in hospital."

"Fantastic," says Dorien's mother. "How do we go about getting a room there?"

"I'll go and see what I can do to organise it," says Anne.

As well as doctors and nurses there are lots of other people on the ward, for example the 'Child Life Specialists'. Dorien gets to meet one of these now. She says, "Hello Dorien, I am Monique. While you are here with us we will all try to make sure that you know exactly what is going to happen during your examinations.

Some examinations are not nice but the doctor wants to know exactly what the matter with your liver and your other organs. Then there are other examinations that don't hurt a bit such as the x-ray. We will try to explain it all to you. The better prepared you are the less nervous you will be. During the next few days you will have a busy program, Dorien.



But....I don't just talk about examinations. We also do lots of nice things with the children here. You are lucky! Do you know what we have just made in our own kitchen?"

"I've organised it," a voice calls out. Dorien looks puzzled. It is Anne. She tells Dorien's parents, "Luckily there was still a vacant room. They are expecting you now. You could take your luggage there straight away. Dorien will be all right - won't you Dorien?"

"Yes," says Dorien.

"Why are looking so worried Dorien?" says Monique. "Is there anything wrong?"

"No.....yes," stutters Dorien. "My mother hates the smell of chips and now she is going to live at McDonald's....."

"OF COURSE NOT," cries Monique laughingly.

"There is a big difference between the two. The Ronald McDonald House where your parents are staying is nothing like McDonald's where you get hamburgers and chips. The owner of the McDonald's restaurants from America has given the money to build these 'hotels' and so the houses have been named after these restaurants.



Oh - by the way - I wanted to tell you: we've just made some pancakes. It's time to eat. Do you want to come and call the other children? We always eat together in the playroom."

In the meantime Dorien's parents go to have their meal in the restaurant in the hospital.

The following days are busy for Dorien. Examinations, examinations and more examinations. But there are also nice times in the hospital.

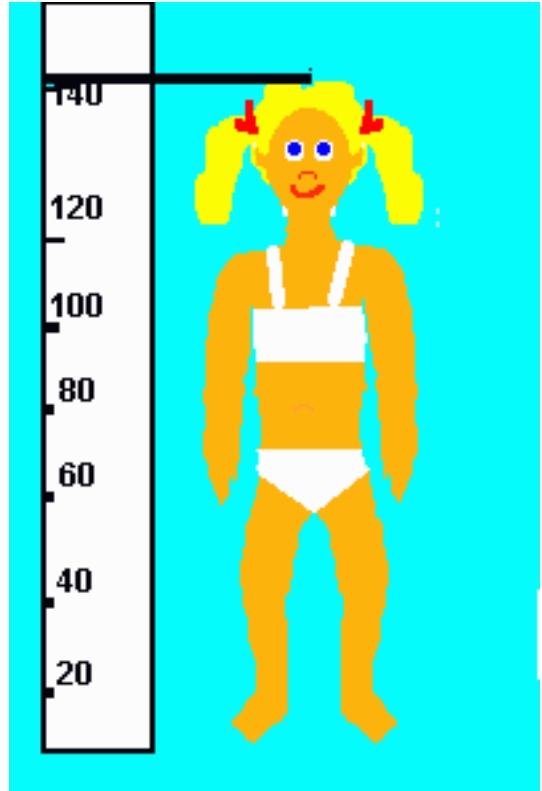
On the third day Dorien gets a room-mate. His name is Karelkje and he is one year younger than Dorien. Now Dorien no longer has the room for herself but on the other hand it is quite nice to have company.

When all the examinations are finished, an appointment is made at the liver transplant clinic. Only then will they get to hear all the results and the answer to the question: "Will Dorien need a liver transplant?" But in the meantime Dorien is allowed to go home!

The secretary has organised all the information on Dorien in a big folder. At the liver transplant meeting all the clever doctors have discussed Dorien's case.

Today is the day. The result! At the clinic Dorien and her parents have an appointment with Dr. Byleveld. He tells Dorien that her name will go on the list for a liver transplant. From today Dorien enters the 'green light' period. Nobody knows when the operation will be performed. Once a month Dorien will have to return to the clinic for tests: blood tests, blood pressure, temperature, weight etc. Luckily she nearly always sees the same people in the transplant team.

Dorien gets to talk with a lot of people. The Child Life Specialist explains certain procedures.



Then the dietician comes along. Dorien will not be allowed to eat certain foods now, and there are certain foods that she must eat.

After that they see a nurse from the liver transplant team and she says, "Dorien is now on the waiting list for a liver transplant but we don't know when it will be her turn."

"Why not?" asks Dorien.

"Well Dorien, it's like this: We don't know when a suitable liver will become available. When that happens we want you to come to Groningen immediately because we can only keep a liver outside the body for a couple of hours.

I will give you a beeper and when it beeps it might be for you. But first ring the hospital, just in case it is a false alarm as sometimes a beeper goes off for no reason at all. So always ring Groningen first to check it out."

When there really is a donor liver for you then you must first take these pills and drink this medicine. We call this pre-medication. These are special medicines that you have to take a few hours before the operation. Then come to us as soon as you can.

Oh yes, before I forget: It would be a good idea to have your bags packed and ready at home, with all your special things in it such as your pyjamas, toothbrush and special toy. When you are called up to go to Groningen, which could come quite unexpectedly, at least you will have everything ready.



Sippy the Child Life Specialist comes to see Dorien each time she has to go for an examination. There she is - thank goodness at least she won't talk about the examination. "Hi Dorien," she says. "I heard that you're on the waiting list! Should I tell you a little bit about your operation?"

'Gee,' thinks Dorien, 'again! I've had enough for today.' But this time Sippy has brought along a doll which she bought in America. It is a special doll to help prepare children for their operations.

Dorien can see for herself how everything looks inside the body, the lungs, the heart, the kidneys, the stomach, the intestines and of course..... the liver. Dorien didn't know that a healthy liver could be so big.

"Well, I think that you have seen and heard enough for today. But wait - here I've got something for you." Sippy gives a small, purple booklet to Dorien. "Read this together with your parents. It is about a girl who also needs a liver transplant. In this book you can learn a lot about what happens at a liver transplant.

Should we go and have a look on the ward to see if there is anyone you know? I will make an appointment in my diary for your next visit and then I will tell you some more."

Dorien goes to visit the patients on M2. Luckily there are still some faces that she recognises. In the meantime it has got late and when Dorien gets home she goes to bed. She is tired.

Dorien now has to wait at her house until there is a new liver for her. This is a difficult time for her. She feels weak and tired and her skin is yellow. Therefore a lot of people stare at her on the street. Every day she has to take a lot of medication to keep her illness under control. Just like many people with a liver disease she has an itchy skin. This, she feels, is the biggest nuisance.

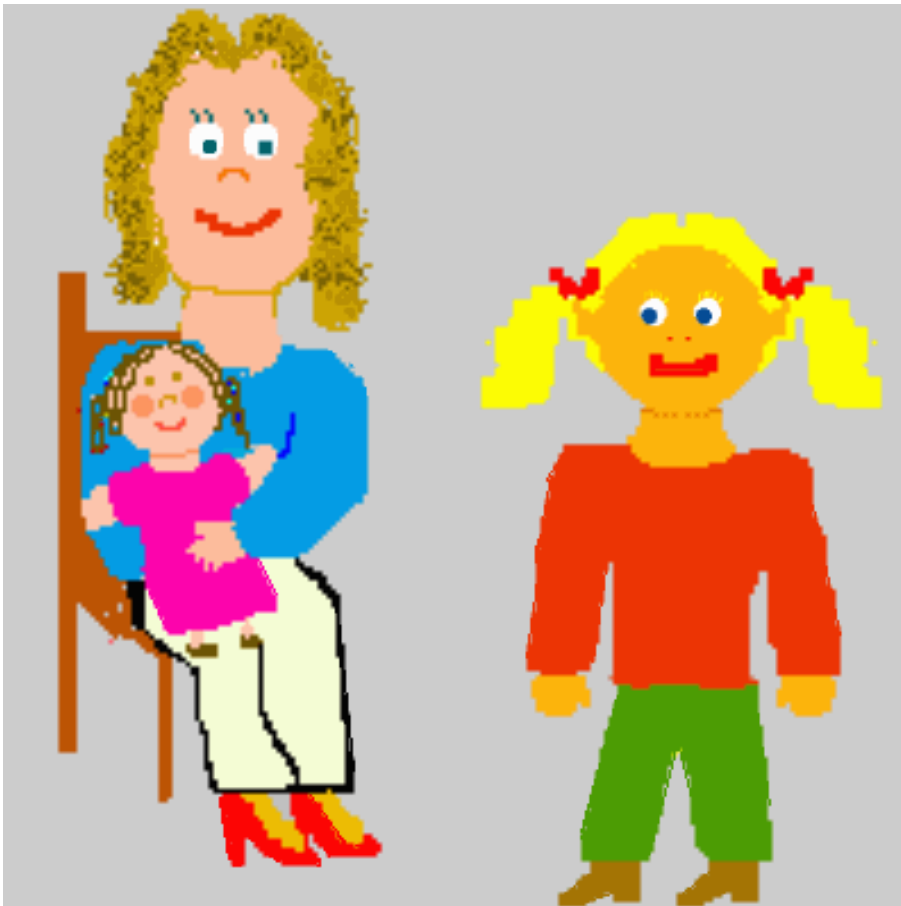
The fact that they constantly have to carry the beeper with them is also making life difficult for Dorien and her parents - in particular during the first few weeks. They have to constantly think about the possibility of getting a call. Then they would have to go to Groningen right away - this makes them rather nervous.

Once every three to four weeks she has to come back to the clinic for a check. Every time she learns a little bit more about her operation. Dorien now knows exactly what is going to happen: When she is operated on her parents will be allowed to bring her to the operating room with her nurse. One of her parents will stay with Dorien until she is asleep.

She won't feel anything at all. When she wakes up she won't be in her ward, the M2, but she will be in the intensive-care unit of the surgical ward.

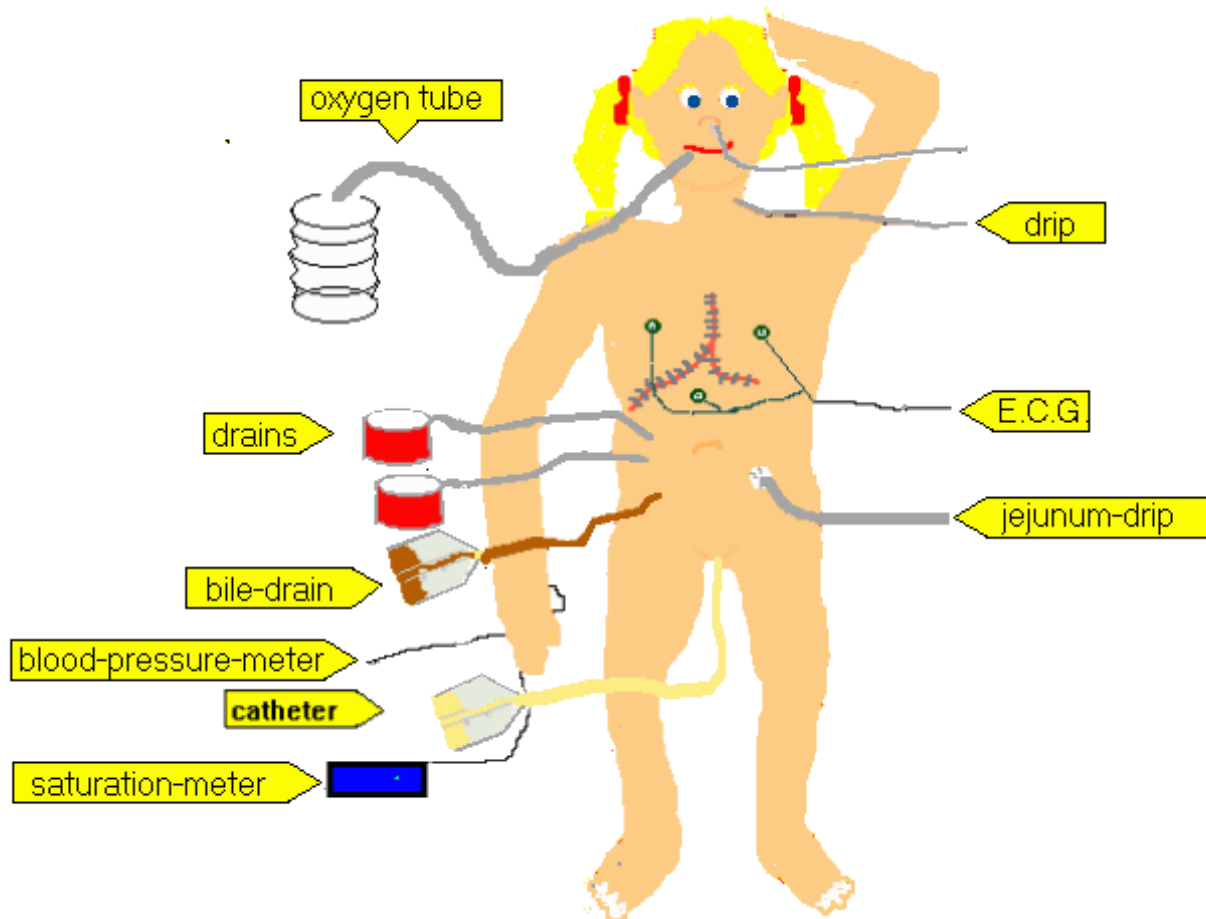
She has had a look at the ward together with her nurse and her parents. She knows that when she wakes up she will have lots of tubes in her and a 'drip' in her arm and she won't be able to talk very well.

One day at the clinic Sippy shows her a doll that has all the tubes and drips just like Dorien will have after the operation.



“Good heavens,” says Dorien, “will I look like that too?” and she was a bit frightened.

“Yes,” says Sippy, “but don't be scared. Most of the tubes will soon be removed when you get better. I'll tell you why you have all these tubes.”



The first tube that will most likely be removed is the one with oxygen. During the operation you will get extra oxygen. And sometimes when you wake up you still have this tube in your mouth. This is what children hate the most because they want to talk and they can't because the tube is there. When you are strong enough to breathe on your own then it will be taken out.

You will also have a sort of 'drip' in your neck. This way your medicine can go straight into your blood-stream. Later on you will have this 'drip' put in your arm.

The little tube in your nose and throat allow the medicine to go straight to your stomach. The saturation meter is a little clip around your finger or your toe. It measures the oxygen in your blood.

The little drainage tubes coming out of the belly collect the fluid from the wound into a little bottle.

You will also have a catheter because in the early stages you will be too weak to go to the toilet to do a wee.

So now we are up to the things that will stay in your body the longest: The bile drain and the jejunum-drip - but it is not sure whether you will actually need them. This will be decided by the surgeon during surgery. The bile which is drained out of your liver comes directly into this little bag. The nurse will empty this bag regularly and the bile will be put back into your body through the 'jejunum-drip'. The jejunum is a part of the small intestines.

"Why do they take the bile out of my body?" asks Dorien.

"Because the new liver is not capable of transporting the bile to the intestines. The new liver has to get used to your body."

Dorien is really overwhelmed and has to think about all this. Finally she asks softly, "Are you sure that the doctors won't leave a tube in me by mistake so that I would have to have that for the rest of my life?"

Sippy puts a hand on Dorien's shoulder and says, "I can guarantee you 100% that they won't do that."

"When will I be able to go home," asks Dorien.

"When the doctors give you the O.K."

"And how long will it be before they give me the O.K.?"

"Well that depends how long it takes for you to get better. You will have to stay in hospital for quite a few weeks."

"And then?" asks Dorien.

"Then normally you will go to a half-way house."

"What is a half-way house?" asks Dorien.

"That," says Sippy with a secret little smile, "is something that I will tell you about next time. I have to see some other children today. See you in a few weeks!"

Dorien waves goodbye to Sippy and then goes to look for her parents. They are talking to a couple of gentlemen. Dorien goes up to them and says, "Hello, I am Dorien."

The gentlemen look up and shake Dorien's hand. "Good afternoon," says one. "I am the surgeon and I will do your operation."

"Hello," says the second gentleman, "I am the anaesthetist, the 'sleep doctor'. I will put you to sleep so that you won't feel and know anything about the operation. We've just come to meet you so we know each other."

The next time Dorien visits the clinic Sippy is there too to see her. "Hi Dorien," she calls out.

"You were going to tell me about the half-way house - remember?" says Dorien.

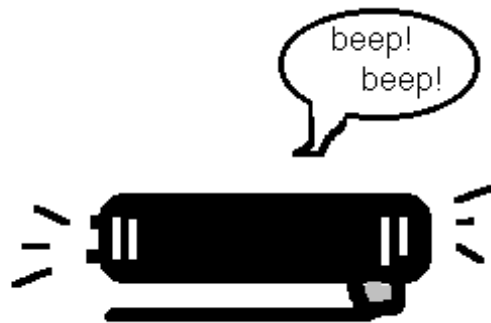
"Right," says Sippy and starts, "the half-way houses are officially called Princess Margriet houses and they are really apartments close to the hospital.

You can imagine that after a major operation such as a liver transplant you are very weak. So you have to build up your energy and strength so that you can do everything for yourself again such as eating, showering, dressing, cleaning your teeth, walking, etc. We just take one step at a time. Especially in the beginning it won't be easy. When you are on the ward the nurses can watch you very closely."

"Yes, yes," says Dorien, "I know all that. Tell me some more about the half-way houses."

“Well I want to tell you about them now,” says Sippy. “In the beginning it is quite frightening to go home with your parents and not have the support of the hospital - the doctors and the nurses and also you have to know and remember lots of things. How and when to take your medicine, how to take your blood pressure, etc. Well, at the half-way house you and your parents will learn all that. So you are nice and close to the hospital but you don’t have to be in the hospital. In the beginning it gives you a sense of security to know that if something did happen you would be close to the hospital. Most families stay one to two weeks. Then they really go home. Now you know what a half-way house is?”

“Yes. Now I know,” says Dorien “Thank you. Bye.”



One day the beeper goes off!

That means that the hospital might have a new liver for Dorien.



While her Dad rings the hospital to see if the call is for real, Dorien’s mother goes off to get her case. Yes, Dorien’s time has come but first she has to have her pre-medication.

Her brother Pim will stay with the neighbour who will take him to his grandmother the very next day.

Here is the taxi already! The three of them go off to the hospital.

Once they arrive there, Arjen, the male nurse is waiting for them. Dorien remembers him from the screening period. He takes them up to her room.

Her parents are able to stay in the Ronald McDonald House again.

Dorien's blood pressure and temperature are taken and then someone comes to do a blood test. She tries to be really brave.

Dorien is not allowed to eat or drink now as her stomach must be empty.



Arjen comes in now with a bottle of special soap. He says, "This is Chlorohexidine soap. You will have to wash with this soap to be really clean for the operation. Would you like to have a bath or a shower?" Dorien decides to have a shower.

She is really pleased when she sees Sippy.

"Are you nervous?" Sippy asks.

"Yes," says Dorien, "I am."

"Do you want me to go over it one more time or would you rather do something else? You tell me what you'd like to do."

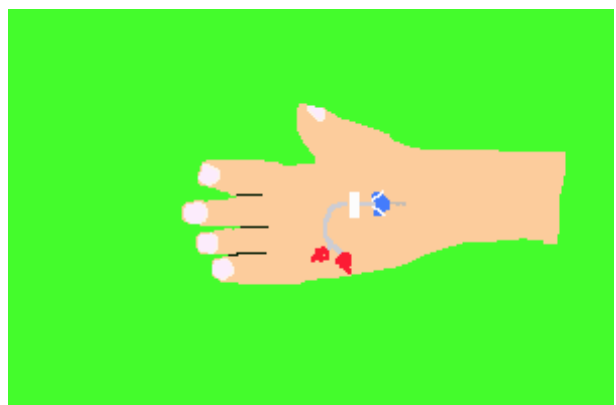
Dorien knows it all. She knows what is going to happen - she has been waiting for this for such a long time.

"No, I'd rather do something else - a game or something to take my mind off it a bit," she says.

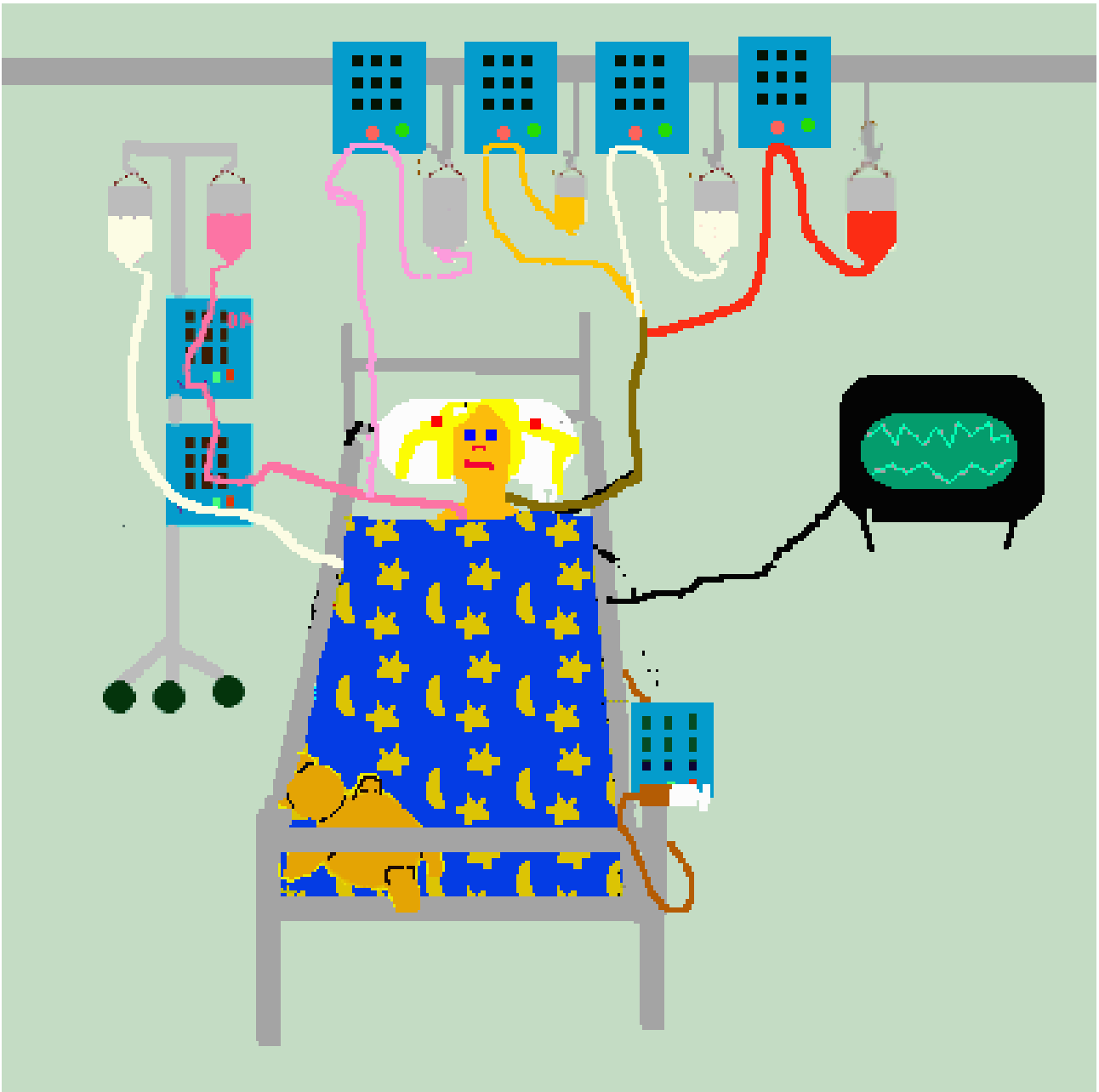
"Ok, let's play a game," says Sippy, "maybe we can find some other kids to join us."

The time has come. Her parents and her nurse take Dorien to the Operating Theatre on her own bed. Her mother comes in with her. In the Operating Theatre everyone is dressed in strange green suits that look like green pyjamas. This is because they want to keep this area as clean (sterile) as possible. Her mum has to put on these strange clothes, too.

Dorien recognises the sleep doctor (the anaesthetist). Now she has to get a needle for the infusion. Luckily she had some special cream on her hand first so that she hardly feels it at all. Then the anaesthetist injects the anaesthetic. It doesn't hurt, it just feels cold. She feels herself getting sleepy. Slowly she sinks into a deeper and deeper sleep.



When Dorian awakes she looks straight into the doctors eyes. Or is it a sister? Dorian can't see so well yet. It all seems rather misty. She tries to say something. But she can't. What time would it be? Dorian has no idea. She decides that it would be easier just to go back to sleep.

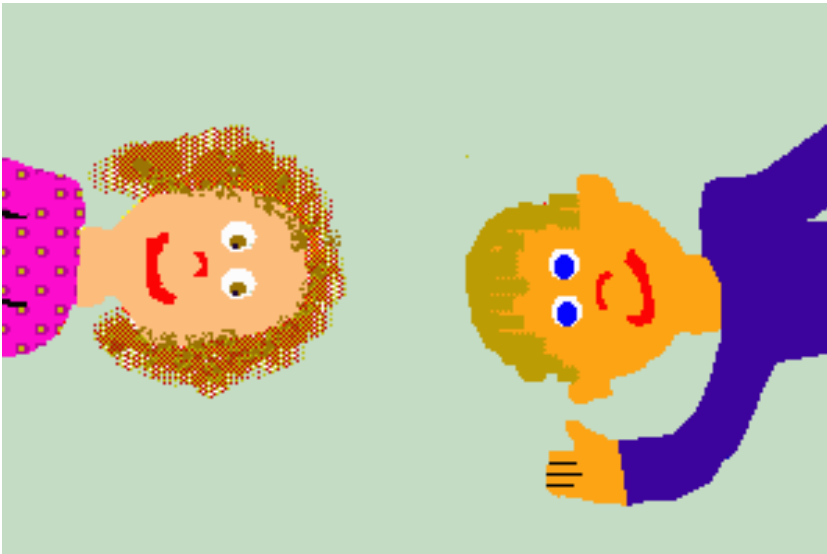


The second time she is awoken by an insistent beeping noise. It must be coming from the blue box that is attached to her bed. It is a kind of pump. Here comes the nurse. She presses on the little box and immediately the noise stops.

Dorien is so thirsty. She wants to ask the nurse if she can have a drink. But she can't talk. Then she tries to explain it with signs. The nurse understands what she wants. "Drink? You are still too weak and sleepy to be drinking yet. But wait - I know something. Here is a wet cotton bud - you can suck on that." It doesn't help much but it is better than nothing.

Again, Dorien opens her eyes. Where is she? Oh yes, she knows. She must have fallen asleep! For a while she just lies there and listens to all the noises. All the pumps and machines are noisy. To her left she hears a soft groan. There is an old man. 'I wonder what is wrong with him,' wonders Dorien.

When she looks to her right she can see a young woman - she is asleep but she has a big bandage on her head. So - on the surgical IC there are adults as well as children.



When Dorien wakes up for the fourth time she vaguely sees the faces of her mother and father and then she is asleep once again.

The days pass and Dorien thinks that there is no end in sight.

Finally - the doctors are satisfied with her progress and they decide that she can be transferred to the children's ward - to her 'own' ward M2.

The early days are not easy for Dorien. This is mainly because she is not able to do very much for herself. She can't walk to the toilet and when she has to go she has to ring the bell so that the nurse can bring her a 'pan'.

Every morning the nursing staff wash her from top to toe. Dorien doesn't like all this very much. She would rather do it herself.



A few times a week the physiotherapist comes to visit Dorien and does exercises with her to encourage her muscles to become strong again. Due to the operation and the long time that she has had in bed the muscles have become very weak. In the beginning she only can manage to sit on the edge of her bed and then she is very pleased to lie down again. After a while she is encouraged to go further and with the help of the physiotherapist she is at last able to take a few steps. Every time she tries to walk a little further. Things are going a little better.....



In the beginning Dorien is not allowed to eat too much. Her stomach too has to recover from major surgery. At first she just has a special liquid diet. Later she is allowed to have some soup, yoghurt, custard and drinks such as lemonade. One day the dietician comes to see her. She says, "Dorien I have good news for you. From today you are allowed to eat normal food. Just take it easy at the beginning and don't eat too many fatty foods. There are still a few things that you won't be allowed to eat. We will make up a list together so you can remember what you can and what you can't eat."

The dietician asks her what she would like to eat for breakfast, dinner and tea in the next few weeks and she also makes a list

of foods that Dorien will not be allowed to eat. Every so often they come to ask Dorien if there is anything that she would like to change or add to her list.

The one thing that Dorien hates is the amount of pills and medicines that she has to take. She has difficulty swallowing the big pills and most of the medicines taste terrible. Dorien knows that she won't have to keep on having all these pills and medicines but she also knows that she will have to take some of them for the rest of her life.



Every week Dorien feels a little better and a little stronger. Slowly, ever so slowly, day by day she can see improvement. She must still stay in hospital for a long time but one day Doctor Byleveld comes to see her. He has good news. "We are very satisfied with your progress," he says. "If your progress continues we will allow you to go to the half-way house next week! Do you know what a 'half-way' house is?" "Yes, I already know that," says Dorien happily.

The next week Dorien and her parents are able to move into the half-way house. Dorien still has to have regular checks at the clinic.

After a little while the big day has arrived!

Finally -

SHE CAN GO HOME.

