paediatric oncology sketched out

52 scenario cards for insight and innovation in healthcare

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What are the current issues in paediatric oncology and how will they lead to new innovations in healthcare?

This combined booklet and set of 52 scenario cards provides a creative toolbox, giving new insights into paediatric oncology. The cards tell the personal stories of families who have been confronted with cancer, as well as the stories of healthcare professionals who work hard to care for these young patients. Each card discusses a topic from different perspectives. People involved in paediatric oncology will recognize many of these issues, and those not familiar with this field will get a glimpse of what the issues are.

We invite you to use these cards to develop innovative design solutions for healthcare. They can also be used as scenario cards in creative sessions and workshops.
When designing healthcare innovations from a people-centred perspective, innovations should fit with people’s experiences and practises. Understanding people and the context for which these innovations are intended takes time and requires empathy. Fieldwork and in-depth interviews are also time consuming and not always easy in healthcare settings; children can feel ill, parents are worried, and professional staff are busy with their important work. These cards provide an insight into some of the contemporary issues in paediatric oncology in the Netherlands. The cards can be used in different ways: as a booklet to browse through or as scenario cards (by taking out the pages) that can be used in creative sessions and workshops.

**HOW WAS IT CREATED?**
To explore the field of paediatric oncology and the opportunities for innovation, we conducted in-depth interviews with different stakeholders about their experiences with paediatric oncology. Stakeholders mostly included parents of patients with childhood cancer and medical practitioners. We also interviewed one survivor of childhood cancer. The analysis involved identifying common themes that we can view from different perspectives. These themes were translated into cartoons and annotated with quotes from the interviewees. The visual impressions arising from the cartoons allow an empathic understanding of the topics, while the quotes allow the grounding of these topics in each unique perspective (i.e., patient, parent and professional).

**HOW TO USE IT**
When envisioning design innovations for healthcare, a common ground is needed to form opinions and negotiate with designers, stakeholders and producers. These scenario cards can provide a space for dialogue and innovation for healthcare. 52 topics are presented in several categories including ‘treatment’, ‘participation’, ‘organisation’ and ‘information’. To allow flexibility, two ‘blanks’ have been added so you can define your own topic and sketch a cartoon.
Below, we present a number of ideas about how the booklet can be used. Use it as an inspirational booklet. Browse through the topics and learn about contemporary issues in paediatric oncology.

**USE IT AS AN INNOVATIVE TOOL**
Use the pages as scenario cards in creative sessions to come up with healthcare innovations. For example by:
- **clustering cards** to pinpoint areas of interest
- **picking-out cards** to conjure design solutions and opportunities for innovation
- **ordering cards** to map-out ‘stories’ from different perspectives.

**ABOUT THE AUTHORS**
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The Princess Máxima Centre for Paediatric Oncology will open in 2016 and will become the largest paediatric oncology centre in Europe. It will function as a worldwide centre of reference, with a focus on excellent care, innovative research and education in the field of paediatric oncology.

Delft University of Technology is a leading Dutch university with an excellent global reputation. Its mission is to deliver science to society and to contribute to the development of sustainable technological solutions for urgent societal problems. Healthcare is one of its four main research themes.

KTH Royal institute of Technology is the largest technical university in Sweden, with research and education ranging from natural sciences to all the branches of engineering, including architectural design, industrial management and urban planning.

EIT ICT Labs is one of the first Knowledge and Innovation Communities set up by the European Institute of Innovation and Technology, as an initiative of the European Union. EIT ICT Labs’ mission is to drive European leadership in ICT innovation for economic growth and quality of life.

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There were bedside TVs so I could watch all of the Olympics while in bed.

You simply accepted that you had to wait for an hour in the hallway, or that you could play there to kill time.

I walked around that stupid souvenir shop endlessly, just to get out.

Sometimes I would watch a movie on our son’s portable DVD player with headphones.
It was sunny outside. I had to walk back to my car and thought, “Gosh, I should go for a walk more often.”

Even if you only had 20 minutes, just sitting outside eating a sandwich, enjoying the sun. Lovely.

I hadn’t been outside for twenty days, so I enjoyed the first spring sun. I can still see myself sitting there, on that bench.

You could sit outside on this huge terrace, near a pond. That was really relaxing.

It was sunny outside. I had to walk back to my car and though, “Gosh, I should go for a walk more often.”
We could be together longer if there was a place where his brother and sister could chill-out. Now they get bored so quickly.

Do things with your family whenever you have the chance; in the weekend go and do something, close to the hospital.

“Everyone asks how my brother is doing…” There should be a special place where his sister can go.

My patient immediately livened up when his sister was with him.

They should pay more attention to the whole family. They should be given respect for the situation they’re in.

It would be perfect if there was somewhere where brothers and sisters could be, somewhere they could enjoy.
Just to be able to get away, to recharge your batteries. After a busy day at work, that would be very welcome.

I love to take time to enjoy a cup of coffee, however I don’t relax while I’m at work.

Getting away from it all, even if only for five minutes: stretch your legs, have a cup of coffee, read a newspaper.

I can relax in my office as well. I can listen to my own music there.

Our office is a place where we can relax; we feel comfortable here - this is our space.
The large spaces and wide hallways can make you feel small and tiny, however small and dark corridors can feel suffocating. Feeling optimistic; leaving the darkness behind. Our staff should radiate, “We’re going for this and we’re going to solve it.”

An ambience which gives each department its own identity, supporting and communicating what happens there. I felt secure because I knew everybody and I knew my way around. At the same time this felt strange because I didn’t want to be here.

Visitors should feel welcome; we should offer comfort and quality. Like in our coffee room with our espresso machine. The large spaces and wide hallways can make you feel small and tiny, however small and dark corridors can feel suffocating.
The hospital shouldn’t be a scary place, but turning it into a theme park is a bit far-fetched.

Our playground is a real ‘Walhalla’. Sometimes, children don’t want to leave the hospital because they enjoy it so much.

Before they die, children still want to get that final ‘hero-bead’.

Children forget that they are ill for a moment if there’s a pet on the ward, they forget they’re a patient for a moment.

Awesome! After our son was discharged, we were allowed on the helicopter deck briefly and played with real walkie-talkies.

We sometimes make cakes together with the children. It’s really special because, while baking, so much happens emotionally.

The hospital shouldn’t be a scary place, but turning it into a theme park is a bit far-fetched.
During a meeting you want to hear as many different opinions about a patient as possible. From a distance, it’s difficult to see whether the children are really developing well. If we knew more about the normal development of children, then we could identify what goes wrong earlier. What’s the value of these huge piles of paper? Don’t tell me that people know what’s in there.

You only arrive at the complete picture of a patient together: the oncologist, physiotherapist, home caregiver, and others. I prepare by going through the electronic patient records and, if necessary, I ask the nurse for more info.
It would be great to contact the nurse by video for 'this' or 'that'. Then she wouldn't have to come over right away.

It would be handy if the nurse could push the button to make video contact with the children, just to see what's going on.

You can't see how urgent it is if you're paged; you can't react.

This would be great, a five-minute pause button on my pager. "She's in, but not available for a moment."

A good thing about email is that parents' questions are clearer and I can answer in my own time.
A nurse is present to make notes. Parents are given a copy so they can read it through when they get home.

Years later, I came across the drawings I made.

I’m glad the nurse is present. After difficult consultations, you can reflect and evaluate how it went.

Often we have to repeat the consultation, as after 5 minutes, people have lost track because of all the information.

Make a drawing of the tumour yourself: you don’t have to be a great artist if you have a drawing tool.

It would be useful if we could listen to what was actually said at the hospital. Then we wouldn’t have any further discussions.
It would be handy if I could check the daily schedule remotely so that I could plan my visit for the quiet part of the day.

We don’t ask parents what’s most convenient for them with respect to their own schedule. We’re really quite inflexible.

With a clear daily schedule, there’s more time for our son to do his own things. “This is my afternoon!”

Make clear when things are planned during the day. Blood tests at 11:00: “Oh, in that case we can still finish our game...”

The teacher always came on time. That was well organised.

It would be handy if I could check the daily schedule remotely so that I could plan my visit for the quiet part of the day.
How do I keep up-to-date on my patients’ progress when they continue their treatment at remote centres?

Parents get frustrated if each shared-care centre has a different policy on nutrition.

I was really irritated when everything needed to be redone. The infusion failed, a new scan had to be made and new blood tests were needed.

You try to keep children on track and then they are transferred. Then you wonder about how much education they receive at the other place.
Make students part of the team and let them experience the real thing in order to learn from it.

They are really curious. It’s rewarding that I am the one who can pass on this knowledge. It keeps me sharp.

The staff must accept students and motivate them. Every staff member was once a student.

Use the Internet to share knowledge and avoid giving long lectures or classes.
It was a relatively small department and I was glad I knew which nurse would be coming. It’s handy if you can see ‘who’s taking care of you today.’ For example, by placing an iPad on the wall that shows staff portraits.

Staff should be able to take on different roles. They should be able to change roles in case we need back-ups.

I didn’t know who was who. When a ‘white coat’ came in the room, I never knew whether it was an oncologist or an assistant.

It was a relatively small department and I was glad I knew which nurse would be coming.

I would like to - and should - see patients more often. Especially if we’re saying, “we are patient-centred.”
You should be able to easily walk in and out of a meeting. People are often paged during a meeting.

It would be valuable to have an overview of the patients to be discussed, and where we’ve got to at the moment.

A good chair allows room for other opinions, and sometimes cuts them off in order to arrive at a mutual understanding.

You should be able to look each other in the eye. Sometimes people have difficulties expressing themselves, due to their emotions.
I don’t eat with the others as often as I should, I don’t have time for it. I’m always in a hurry.

You can only develop professionally if you have time for research and education.

I would like it if the workload was slightly reduced. I’d be happy just being able to take my breaks.

Time pressure makes it difficult to concentrate. I’m glad if I find time to go to the toilet.
They invested everything in me. My parents, as well as my brothers and sisters, were not given the attention they needed.

In my opinion, parents don’t have to stay in the hospital day and night once their child knows its way around.

After our son’s diagnosis, my husband stayed at home while I was in the hospital. We switched every now and then.

We were more apart than together. When looking back, that was extremely tiring.

It’s important to be in the hospital - as a couple - for the first few days. Both for emotional support as well as practical issues.

In my opinion, parents don’t have to stay in the hospital day and night once their child knows its way around.

They invested everything in me. My parents, as well as my brothers and sisters, were not given the attention they needed.
Helping families to continue their everyday life is better than focusing too much on the disease itself.

Encourage parents to look ahead. ‘Later when my child is cured…’ Let them dream about the future, let them make plans.

Use Skype to keep in touch with home and school. For example, have dinner together, remotely.

Maintaining daily routines gives us a sense of security. Take your daughter to school, do the shopping, walk the dog.

Continue to have a normal life, as much as possible. Keep on chatting to your friends, despite hospitalisation.
lack of understanding

"If you're not cured then you didn't do your best." Cancer is a matter of chance and not a matter of choice.

The schoolteacher didn’t use the info and tips I gave her about how to handle a patient in her class. I had the idea she found it difficult.

Our son told his classmates what cancer is about so that they wouldn’t have an unrealistic picture of the disease.

Nobody knows what it’s like to have childhood cancer. Not even if you have children yourself.

Our son told his classmates what cancer is about so that they wouldn’t have an unrealistic picture of the disease.
Families are often split up during cancer treatment. They’re often not really together for eight to ten months.

Small children like to eat what mom and dad are eating. Seeing food encourages you to eat.

As a family, we enjoyed our home-made spaghetti in the playroom.

We were not allowed to cook in the kitchen there, so we brought everything from home.

You want to cook for your own child. This makes life more normal and keeps your feet on the ground.

Families are often split up during cancer treatment. They’re often not really together for eight to ten months.

I like the idea of a parent’s kitchen, but I’d rather eat in my child’s room if he wants to stay in bed.

Small children like to eat what mom and dad are eating. Seeing food encourages you to eat.
I've got so far behind with school that I'll never catch up. In that case, I'd rather drop school completely.

If you lag behind at school you feel like an outsider. The entire family is affected by it.

At the hospital school, you work with the healthy side of children. School is familiar to them. They feel free here.

A bright and familiar school atmosphere: the same tables as at their own school, the same posters on the wall.

Keep on pushing patients to attend school because the aim is to help the children and not the parents.

I've got so far behind with school that I'll never catch up. In that case, I'd rather drop school completely.

If you lag behind at school you feel like an outsider. The entire family is affected by it.
If the situation gets emotional, you only focus on your child and not on the stupid drugs.

We knew exactly which medication he was given, almost to a morbid extent.

You need to be on top of it. I’ve managed to prevent countless errors. They connected the drip in the wrong way.

I find the technical aspects of the infusion pump interesting. It gives me something to do and a sense of control.

Your child is being treated. You can’t relax. You always have a certain level of alertness that you want to retain.

If the situation gets emotional, you only focus on your child and not on the stupid drugs.
Stressful situations can be avoided if parents, children and the nurses communicate properly.

With paediatrics, it’s very much about talking to parents, but it’s also important to involve the children in conversations as well.

When I enter the patient’s room, I always try to explain why I am here. Even at night, when the parents are awake.

Clinicians should approach parents much more proactively. We are quickly aware of whether our child is doing well or not.

The nurse taught us how to do things so that we could do them at home, ourselves.

A good point is that they listened to us, what we thought of something, and what we experienced.

With paediatrics, it’s very much about talking to parents, but it’s also important to involve the children in conversations as well.

Stressful situations can be avoided if parents, children and the nurses communicate properly.
The parents didn’t want us to have a look at their child at night. But we have to – that’s part of our duties.

Parents sometimes need to be reminded to clean their room. It can be such a mess that you don’t know where to start.

You sometimes meet families who claim the parent’s room and who are so negative that they ruin the atmosphere for other parents.

The nursing staff didn’t agree with our choice not to eat together as a family. This is something we should be able to decide for ourselves!

At night, some idiot was annoyed with me for lowering the speed of the drip myself. The drip’s alarm was constantly on.
Some nurses walk around all day long wearing perfume while they know that the children really don’t like this!

When we arrived at the ICU, the doctor said, “I’m not going to tell you anything now because my shift is done.” I was completely mortified!

If I didn’t agree with the therapy, she threatened to deprive me of my parental rights.

When we arrived at the ICU, the doctor said, “I’m not going to tell you anything now because my shift is done.” I was completely mortified!

If you say, “I have to refresh the drip but I’ll do it as quietly as possible” then you’ve already won our sympathy.
How open and honest can you be if parents participate in staff meetings? You could miss some important things.

Let us think with you! You also don’t know what to do. If you leave us out of things, I’ll take him away from this hospital.

I really had to fight to find out what they wanted to do. “Hey, I’ve also got a degree!”

It’s hard to know what to do when a new treatment therapy protocol is proposed, without prior consultation. What space do I have as a parent to say “no”? How open and honest can you be if parents participate in staff meetings? You could miss some important things.
I got nauseous from the smell of other peoples food. Even the sound of knives and forks made me feel sick.

We couldn’t eat a chilli hotdog with him in the patient room - we would disturb him.

What once tasted good now tastes bad; everything changes.

Our son said, “I’m not going to eat anymore in the hospital. It stinks! I’ll only drink water.”

We couldn’t eat a chilli hotdog with him in the patient room - we would disturb him.
What once tasted good now tastes bad; everything changes.
The microwave was too dirty to handle.

There was only one toilet for all the parents.

Cleaning the rooms could be done 10,000 times better. The dust behind the TV was clearly visible. Of course this shouldn’t be allowed to happen.
When I arrived I saw it, the children’s oncology department. I was really appalled.

From that moment on I didn’t remember much... It was very intense.

We arrived for the first time on Monday night. The ward was abandoned and empty; a miserable place.

Parents are scared to death when they arrive at the ward and they see all those little bald heads and IV drip holders.

The first contact is really important. You take them under your wing. If you do that well, they’re less panicky later on.
In each other’s presence, parents and children don’t reveal their true feelings.

Parents should really be able to focus during a consultation and this becomes difficult if the child is asking for attention.

I couldn’t say the words ‘tumour’ and ‘lung’ in the presence of my child.

You don’t easily leave your child to the care of a stranger. It depends on whether you feel you can trust that person.

He couldn’t go anywhere... not the playroom, not the hallway, nor could he leave the ward.

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In each other’s presence, parents and children don’t reveal their true feelings.

I couldn’t say the words ‘tumour’ and ‘lung’ in the presence of my child.
Consultation rooms need to be quickly and easily adapted to the type of consultation.

Everyone sticks things on pagers. I put a small good-luck charm on mine.

I don’t mind sharing my workplace with colleagues. So flexible workplaces are fine, but they should be easy to adapt.

Consultation rooms need to be quickly and easily adapted to the type of consultation.
consultation room

Neutral with few associations attached to it. Not too crowded and personal. Quiet places, providing a safe feeling.

Create a small play area so parents can concentrate on the conversation when children are present.

A large table to sit around together and a large screen on which you can show the tumour.

There shouldn’t be anything hanging that doesn’t fit the setting. No glaring posters.

No small and narrow rooms. No dark, unwelcoming spaces without windows.

Neutral with few associations attached to it. Not too crowded and personal. Quiet places, providing a safe feeling.
The canteen is too far away, busy and expensive. It’s also chaotic there. It takes too much out of me to go, so I never do.

You should be able to park your car without it costing 100 Euros per hour.

With the lifts, it takes 5-10 minutes before you get to the meeting room.

During the breaks, there are long queues of people who are not ‘white coats’.

You had to reserve a table before twelve o’clock if you wanted to have dinner in the canteen.

You cannot normally sit down or leave the canteen. It’s that crowded.

The canteen is too far away, busy and expensive. It’s also chaotic there. It takes too much out of me to go, so I never do.
Nurses should also be able to stay overnight. A bed, a cupboard and Wi-Fi is enough. As a parent you sleep on a couch. It’s just hard to lie down on it. You really don’t get any sleep. Now the food is served in the room where you have to go to the toilet. That’s very unpleasant. A fridge would be ideal because our son wanted to eat his own things, like strawberries with whipped cream.
Well-integrated recording equipment so that clients don’t feel threatened when a conversation is being recorded for research.

Equipment should be easy to handle. Press on the button and start; no preparation.

An iPad that you can put on the table gives a different feel than when you sit behind your PC that the client cannot see.

I often turn my computer screen towards the parents so that they can see the blood test results.

At the head of the table there is a large screen where you can present images and the patient data.

I don’t even use that large computer screen. It takes too long to install and to login.
The more you can stay in the present, the better you can manage emotions. It prevents you from taking them with you.

Express your sadness the moment you feel it. Find quiet places, be able to be alone.

One thing I miss is a place where you can just let yourself go, completely.

The first time I could really express my emotions was in the shower, until someone knocked on the door.

Sometimes you just need to go somewhere where no one can bother you: a soundproof space where you can scream your lungs out.

The more you can stay in the present, the better you can manage emotions. It prevents you from taking them with you.
Learn to live by the day. Be there for each other. Pick out the positive aspects of negative experiences.

When we received the bad news, we felt like falling through the floor. We lost all sense of reality.

Don’t neglect yourself. Try not to feel sorry for yourself.

This experience has made our world a lot bigger. I’ve become much more assertive.

You balanced between life and death: look how you have coped with it together - this deserves respect.
They only intervene when it escalates, but you try to prevent this from happening. It would be good if you had contact with a 'family coach', someone who acts as a kind of intermediary. In the beginning everyone is interested in you, but after two months this stops, and you can no longer ask for help from social work. We needed help managing our finances.

We were in need of someone who would sit down with us and ask: “What do you really need?” They only intervene when it escalates, but you try to prevent this from happening. It’s good if you can talk to a professional about the emotional aspects of work. This is especially important for beginners.
We would organize a meeting if something stressful occurred. Close the door, and handover your pagers. People sometimes underestimate the emotions that go with this job. “Shared sorrow is half the sorrow.”

At times you need someone, someone who knows what has happened, someone with who you can share your experiences. I have occasionally told my story to others, sharing experiences. In this way you try to comfort each other.

I was helped so much by joking with other parents. It was such a release.
I believe in the strength of the ‘Friday afternoon drink’. This is important, especially for colleagues who don’t see each other that often.

In the ‘doctors mess’ you’re together with other doctors; you can have a laugh and a moan, outside the medical context.

Enjoy contact with colleagues on Facebook - just, chitchatting about nothing in particular.

A group of boys aged about ten were doing embroidery together on the ward. They had so much fun together.

It’s not much fun having lunch in a room where parents and patients are also eating. They’re always bothering you with questions.

You could get a cup of coffee and sit down together in that corner in the hallway, the family room was just too far away.
It’s rewarding when you see a patient noticing that people work together well, that there’s no fuss. That also helps me cope.

To work together well, you need to know what to expect from each other and that you should be service-minded and proactive.

Doctors are often solitary beings, it’s in their culture. They should change this I think.

It’s rewarding when you see a patient noticing that people work together well, that there’s no fuss. That also helps me cope.

You feel secure when you see that the oncologist knows what the surgeon is doing and that the surgeon knows what the oncologist is doing.

When you’re dependent on the goodwill of others, then you need to have a clear story and need to have ‘tact’.
Sometimes you shared a room with a Moroccan, and then the whole family would visit together, all at once. That wasn’t always pleasant.

There are many children with foreign roots; we have a lot of language issues. We invite an interpreter to deal with any language barriers. Nurses should be aware that they are also a ‘guest’ when visiting patients and family. Each family has its own culture.

Sometimes you shared a room with a Moroccan, and then the whole family would visit together, all at once. That wasn’t always pleasant.
I realize that, if their child passes away, I become part of a family’s collective memory. Pay attention to the family; celebrate the small things in life. Offer a piece of cake when it’s brother or sister’s birthday.

I try to often compliment the staff. That’s very important, because it makes people feel at ease.

Becoming too emotionally involved with patients is not the right way of acknowledging them: a border has been crossed.

The janitor was such a great guy. He always played soccer with him. It is important when people show compassion.

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Pay attention to the family, celebrate the small things in life. Offer a piece of cake when it’s brother or sister’s birthday.

I realize that, if their child passes away, I become part of a family’s collective memory.
Areas should be made available for parents where they can have some privacy, for example special corners in the parent’s room.

I couldn’t find any place to phone in private. At a certain moment I made a call in the storage room.

When I called home, I didn’t want my son to hear our conversation. So, I quickly made calls in the stairwell.
Because you want to get better, you succumb to your situation; this makes the nurses friendlier and increases the quality of care. Parents are more open to you if they trust you. Gaining their trust is like an investment that you get back, a kind of social currency.

Parents should immediately feel at ease; provide a personal welcome and guide them directly to the appropriate department.

I can let go if our son is approached as a ‘person’ and not as a ‘patient’. If I see otherwise, I become critical and picky.

There was a positive attitude “We’ll do everything we can to cure him.” This was immediately reassuring.

Because you want to get better, you succumb to your situation; this makes the nurses friendlier and increases the quality of care.

Our relationship with the oncologist is based on mutual respect. She listens well to us and talks to our son.

Parents are more open to you if they trust you. Gaining their trust is like an investment that you get back, a kind of social currency.

Parents should immediately feel at ease; provide a personal welcome and guide them directly to the appropriate department.
The first hour of treatment feels the worst. The medication actually makes you ill.

They said “it doesn’t hurt that much.” Well it did! Honesty was really important to us.

The treatment really sucks, and there’s no way to make it less awful.

You don’t want to delay bad news nor do you want to make it ‘woolly’. Children age 12 and older should be allowed to hear the truth.

Keep on stimulating teenagers but don’t pamper them. Give them the some space to chill-out.

The childcare worker was continuously waving her magic wand. It drove us crazy. I felt like, “leave him alone.”
By making pill-taking into a kind of game, in the fantasy world we created, I managed to swallow my medicine.

For small children, ‘fantasy meals’ work very well, for example ‘Princess Pasta’ or a ‘Bob the Builder’ meal.

They consistently called the radiotherapy apparatus a ‘carwash’ to make the machine less frightening. This worked well.

We read adventure stories endlessly, stories about someone who perseveres and overcomes difficulties.
Going down that dark corridor at night with just the two of us; that was exciting! Luckily we had bikes in the corridors, I’d run after them with my IV drip-holder: that was fun!

We played football in the hallway. That was a lovely sight. It felt great to be out of that small room for a moment.

Organising ‘wheelchair races’ or discovering new hallways on crutches. Every building offers plenty of opportunities.

It’s important that patients get out of their room.

Going down that dark corridor at night with just the two of us, that was exciting!

Luckily we had bikes in the corridors, I’d run after them with my IV drip-holder: that was fun!

We played football in the hallway. That was a lovely sight. It felt great to be out of that small room for a moment.
If I were to explore and discover, games with different meanings for different ages. I would offer meals as separate parts, then the children could make up their own combinations.

He would only take his pills when he could choose where to take them.

When our son could choose how he wanted to be anesthetized, he didn’t make a fuss. I would offer meals as separate parts, then the children could make up their own combinations.

Nice to explore and discover, games with different meanings for different ages.
At times when the nauseousness was bearable, all I did was play games on my laptop, just simply gaming.

It was fun to see what was happening on the corridor. I always enjoyed that.

It’s perhaps a little too optimistic to think that children will show a lot of initiative.

Having rest should not become a form of isolation. What’s happening in the outside world must remain visible.

Sometimes they don’t want to do anything. I was quite happy when he simply managed to do something simple.
It’s a real burden for parents when I ask them all these questions about consent. I feel really hesitant about asking: half of them say no. It’s all quite complex, all those questions. It should be possible to make it easier, for example by using video, or a DVD.

There were parents who said, “Please stop. I think I’ve had enough for the time being, I’ve enough to cope with as it is!”

I think a lot of parents want to cooperate, but that they have to be asked at the right time, for example in the evening.

In the first period, you’re pretty selfish. There’s no room for anything other than the survival of our son.
During a meeting you want to hear as many different opinions about a patient as possible. From a distance, it's difficult to see whether the children are really developing well. You only arrive at the complete picture of a patient together: the oncologist, physiotherapist, home caregiver, and others.

I prepare by going through the electronic patient records and, if necessary, I ask the nurse for more info.

If we knew more about the normal development of children, then we could identify what goes wrong earlier.

What's the value of these huge piles of paper! Don't tell me that people know what's in there.

Forms! Chaos! Endless stacks of paper. Following tight rules that feel unnecessary.

You have neither time nor inclination. I have to motivate others to do something that I myself find meaningless.

Confusion! Each department has its own point of contact: “Who has created these barriers?”
During a meeting you want to hear as many different opinions about a patient as possible. From a distance, it’s difficult to see whether the children are really developing well. You only arrive at the complete picture of a patient together: the oncologist, physiotherapist, home caregiver, and others.

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We do our best to keep parents in touch with the results of the research programme. For example, through newsletters.

We must always provide evidence in our profession: research allows us to do so.
SKETCH YOUR OWN

use these two ‘blanks’ to define your own topic and to sketch a cartoon ››