

(to be seen
is to be held)

What does it mean to photograph in the context of illness and what questions of care and representation come with this act?

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1. Prologue

I have been a sick child. I know what it is like to be looked at: not for who you are, but for what you have. To be seen through the eyes of doctors and nurses, through the worry of your parents, through the curious glances of other children. I know how it feels when your body doesn't work with you but against you. When you sense the sadness in your family that you cannot fix, even though you are the reason for it. When you see love and desperation coexist in the same faces around your bed. When your little sibling feels left out and you can't help but know that your illness takes up more space than it should.

I know the quiet loneliness of that kind of visibility. Of being seen for what is wrong, not for what is whole. Those experiences never really leave. Even years later, something as simple as a small sports injury can bring back the same feeling of fragility: the memory of being that sick child again.

These memories are not only personal, they are part of how I see and how I photograph. They have shaped my sensitivity toward others who live with illness in how I approach them, how I look and how I hold the camera. Photography, for me, is not just about representation but about recognition: about seeing someone as more than their diagnosis, more than the label of a patient.

With my graduation project, for which this research forms the foundation, I want to give the children I photograph something I once longed for myself: the feeling of being seen as a person, not as a condition. To be photographed not because of illness, but despite it. Because you cannot choose your illness, you have to live through it and make the best of it. And sometimes, the best looks radiant and full of strength. And sometimes, the best is simply the one percent you have left to give.

This research is my way of learning how to do that responsibly. How to photograph with empathy, respect and care. It is an exploration of ethics but also of presence. Of what it means to look at another human being and to truly see them: not for what is wrong, but for who they are.

2. Introduction

Photographing people who are ill or otherwise vulnerable always brings ethical questions. It is not only about how the images look but also about the experience of making them and being part of them. In this research paper, I want to study the ethics, methods and experiences of photographing people dealing with illness. My focus will be on patients and people living with illness and the photographers personal, not on the wider influence these images might have on society. What interests me most are the direct experiences of photographers and subjects: what it feels like to photograph and to be photographed in these situations, and the ethical challenges that come with it.

This subject connects strongly to my own practice. I am a portrait photographer, not a documentary or still life photographer. Portraits always involve a personal relationship between photographer and subject and I want to explore how that relationship works when illness becomes part of the picture. My choice of this topic also comes from a personal history: I experienced illness myself as a child. Spending time in hospitals and being looked at, sometimes through medical eyes, sometimes through the eyes of family or friends, made me very aware of how it feels to be seen in vulnerable moments. These memories shaped my sensitivity to the act of photographing others and my awareness that a camera can both connect and distance people. Through this research I want to revisit those early experiences not as a patient but as an image-maker: someone who now holds the camera and carries responsibility for how others are seen.

Because of that, this paper is not only an academic exercise but also a way for me to educate myself. I want to better understand what it means to work ethically as a photographer. Not just in theory, but in the emotional and practical reality of making portraits. The process of writing, reading and interviewing will guide me in shaping a more conscious approach for my graduation project where I also plan to work with children whose lives are affected by illness. The research is therefore both preparation and reflection, it is a foundation that helps me navigate sensitive encounters and make decisions that respect the people I will photograph.

The range of the research will be clearly defined. When I use the word “vulnerable people,” I mean mostly patients or people dealing with physical illness. I will not focus on healthcare workers or on other types of vulnerability such as refugees or unhoused people. The central genre is portrait photography, because this is my own field of work.

The research will have three main parts. The first part is theoretical. I will look at what ethics are and how the history of ethics has been discussed in photography. The second part is fieldwork. I will conduct semi-structured interviews with photographers who have worked on projects about illness. Semi-structured interviews mean that I will prepare guiding questions but also give space for the interviewees to speak freely about their experiences. In these conversations I want to understand the struggles, the emotional impact, the bonds that were created and what felt comfortable or uncomfortable. The third part will be visual analysis. I will study a selection of photography projects about illness and ask how they worked and what choices were made.

This research is relevant because the act of photographing ill people is common, but the voices connected to it are not often studied in detail. Many discussions focus more on how society sees these images and therefore, while less attention is given to the direct experiences of those involved in making them. By listening to these sides, I hope to bring more understanding of the ethical dimensions and the emotional labour in this practice.

In the end, I will conclude what I have learned and how this connects back to my own graduation project and my own general practice. But I also hope that my findings can be valuable for others: for photographers who want to work in sensitive fields and for subjects who wonder what it means to be photographed in vulnerable times. My aim is that this research does not only support my own practice but also contributes to a more careful and respectful way of photographing vulnerable people.

3. What ethical frameworks and literate perspectives exist around the representation of illness in photography?

3.1 What are ethics?

Before I can explore the ethical dimensions of photographing illness, it is important to first understand what *ethics* actually means. Ethics, as defined by Evers (2012) in *Media-ethiek: Morele dilemma's in journalistiek, communicatie en reclame*, is “the systematic reflection on moral questions that arise in concrete practices.” In other words, ethics is not something abstract or distant. It is rooted in the real actions and decisions we make in our professional and creative work. Evers emphasizes the **context of action**: moral judgements are never neutral but always connected to the specific situations in which they occur. He distinguishes three levels of ethical reflection:

- The normative level, which concerns values and moral principles.
- The empirical level, which deals with what people actually do in practice.
- The reflective level, which involves critically analyzing our actions and their contexts.

This framework fits well within the field of photography. When making portraits, especially of people who are ill, we are constantly asking ourselves questions of action, intention and consequence: what we do (to photograph), why we do it (our motivation or purpose) and what the impact is (on both the subject and the viewer).

Building on this, Verhofstadt (2019) describes ethics as a **relational process** instead of a fixed set of rules. In his view, ethical practice means continuously balancing between interests, power and vulnerability. He introduces notions such as media accountability and interpersonal care, both of which are especially relevant when photographing people in fragile or intimate situations. Verhofstadt also frames media ethics as a kind of *'moral craftsmanship'*: the ability to act both empathically and critically in situations that involve moral tension.

From these perspectives, I define ethics as **the reflective processes and relational practices through which individuals decide how to act responsibly towards others in contexts of representation, vulnerability and power**. This understanding forms the foundation of my research into the ethics of photographing illness.

3.2 A Brief History of Ethics and Representation

The idea of *ethics* has a long history, coming from questions about how to live a good life into frameworks that guide professional and creative practices today. In early philosophy, **Aristotle** (1999) described ethics as the ‘cultivation of virtue’, which means learning through experience and practice how to act well in relation to others. His view focused on *character* rather than strict rules, which makes it very relevant to creative fields such as photography, where intuition and sensitivity often play a large role.

Later philosophers such as **Immanuel Kant** (2012) and **John Stuart Mill** (2009) proposed two of the main moral frameworks that still shape ethical thinking today. Kant’s approach emphasizes moral duty and universal principles: an action is good if it follows a rule that could be applied to everyone. Mill defines ethical behavior by the weight of its consequences. These theories might seem far removed from photography, but they offer two different ways of thinking about moral action. Following principles versus weighing outcomes.

Nowadays ethics has shifted toward situational and relational understandings. Instead of focusing only on universal laws, thinkers now emphasize empathy, responsibility and care within specific contexts. This approach resonates with the media ethics of **Evers (2012)** and **Verhofstadt (2019)**, who both highlight that moral reflection must always consider relationships between people and the power structures that shape them. For photographers, this means that ethics cannot be separated from practice. It comes from within the encounter between the photographer and the person being photographed.

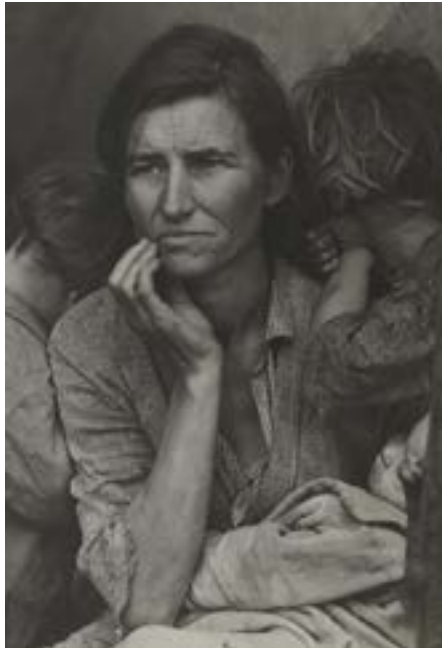
When photography was invented in the nineteenth century, it immediately became connected to notions of **truth and representation**. Photographers such as **Jacob Riis** (1890) used the camera to document poverty in New York’s tenements. He believed that making suffering visible could inspire social change. **Dorothea Lange’s** (1939) *Migrant Mother* became an icon of the Great Depression, revealing the power and the tension inherent in documentary photography. While these projects aimed to raise awareness, they also revealed ethical dilemmas: who gets to look at whom and how much control does the subject have over their own image?

These questions are still important today. As **Susan Sontag** (2004) wrote in *Regarding the Pain of Others*, photographs of suffering can provoke empathy and desensitization at the same time. Images may inform viewers about realities they cannot otherwise witness, but they can also aestheticize or exploit pain. The ethical challenge lies in balancing visibility and respect, in showing without

objectifying.

To understand why this matters, it is helpful to see photography not just as a form of documentation, but as what **Mitchell (2006)** calls ‘a living image’ in the book *What Do Pictures Want?* Mitchell suggests that pictures have their own “lives and desires”. They circulate, influence and act upon viewers. Once an image is made it continues to exist beyond the photographer’s intention, shaping perceptions of its subject in ways that are not always predictable or controllable.

In this sense, the history of ethics and representation meet in photography. The central question stays the same: **how should we act responsibly toward others?** Photography simply translates this question into visual form. Every portrait involves choices in what to show, what to conceal and how to represent another person’s reality. In the context of illness, these choices become even more charged, asking not only for artistic sensitivity but also an awareness of power, vulnerability and care.



(Lange, 1936)



(Riis, 1872)

3.3 From ethics to care: contemporary thinking on photography and representation

While ethics offers a theoretical framework for thinking about responsibility and representation, it often remains abstract and based on rules. In photography and media, people who are ill are often shown in limited and stereotypical ways, for example as weak, passive, or defined only by their illness. They are often portrayed either as victims, focused on suffering and vulnerability, or as “fighters” and “heroes.” Although these images may seem very different, they both reduce a complex experience to a single story. As a result, the person behind the illness can disappear and illness becomes their main identity instead of just one part of their life.

This shows that ethical questions are not only about what is right or wrong, but also about how people are seen and understood.

In the practice of photographing people who are ill, the questions that come up are therefore not only about moral correctness but about sensitivity, presence, care and attention. It is about how to care for the other through the act of looking. In this way, the discussion of ethics can be followed through the concept of care, which brings a more relational and affective understanding to the act of photographing and being photographed.

Care theory, as described by professor and political theorist Joan Tronto (1993) and researcher María Puig de la Bellacasa (2017), shifts the focus from rules to real relationships. Tronto defines care as “a species activity that includes everything we do to maintain, continue and repair our world,” which means that care always involves practice like doing, noticing, responding. Puig de la Bellacasa adds that care does not need to

be only neutral or soft. It can be demanding, messy and deeply mixed with power. What matters is attentiveness: the willingness to stay with someone’s reality without absorbing it or turning it into something decorative. This is crucial in photography about illness, where the camera is not just a recording device but part of a shared encounter. Care enters at multiple stages of the process: in how you approach someone, how you listen, what you choose to include (or exclude), and how the final image circulates. It requires a slower way of working. It also means accepting that not everything should be visible and that care can also be present in what remains unshown. It is a method that protects vulnerability

rather than amplifying it.

By linking ethics to care, the conversation moves from “What is the right thing to do?” to “How do I remain attentive and responsible within this specific encounter?” This relational approach does not replace ethical thinking, it grounds it. It makes it practical.

3.4 Concluding: what is the relationship between photography, care and representation?

Looking back at the theories and ideas discussed in this chapter, I find that the relationship between photography, care and representation is not something fixed or defined by one clear rule. It is something that grows between the encounter of the photographer and subject. Ethics gave me the language to understand responsibility and power but care gave me a way to actually work with those ideas in practice. Where ethics asks “What should I do?”, care asks “How do I stay attentive to this person, right now, in this moment?”. That is what makes everything more grounded and more human.

Throughout this research I became aware again that representation is never neutral. Every image carries traces of the choices a photographer makes. How they approach someone, how they listen, where they place their self in the room, what they allow the camera to reveal and what they protect. In the context of illness, these choices become even more sensitive. Care is not only a feeling, it is an active practice. It shows in the slowness of working, in asking permission again and again and in staying open to discomfort and in accepting that some things are not mine to photograph.

Writing this chapter forced me to look at my own work with more distance, but also with more honesty. I realized that many instincts I already had in portraiture like slowing down, having long conversations, allowing silence, making images together instead of of someone are actually forms of care. I just never had the words for them. Thinking through ethics helped me see why certain moments during shoots felt morally complicated, even when nothing “wrong” happened. Understanding care showed me how to respond in the future to those moments in a way that feels more grounded and intentional, I hope I can apply it. It made me aware that good portraiture is not only about aesthetic decisions but also about relational responsibility. The camera is a tool for me, but it is also a presence. It can easily take space or it can make room.

This chapter also made me more aware of power and that as a photographer, I always hold more of it. Even though I do not look at myself as a powerful person, I am a short and young woman, the camera

gives you power. Power and responsibility. Care becomes the method for balancing that, for making sure my presence does not dominate the encounter. It gives me a way to think about boundaries, consent and emotional labour not as obstacles, but as part of a practice that shapes more honest, and therefore maybe even better, images.

4. What approaches and considerations guide photographers working with the representation of illness and how do their methods reflect care in their practice?

This chapter looks at this question through interviews on four different projects: Henrik Malmström's *On Borrowed Time*, Reinier van der Lingen's long-term documentary approach, Frida Lisa Carstensen Jersø's self-portrait project *Frida Forever* and an informal conversation with Sarah Julia Wong about *Sophia's Children*. Each of them photographs illness from a different position: a family member, outsider, patient and long-term visitor. They show that care in photography isn't one method or one attitude.

As I prepare for my own graduation project in a children's hospital, I'm looking for more than aesthetic references. I'm looking for ways of working that help me keep the children's agency, dignity and personhood at the center. These interviews show me where my own instincts sit in that spectrum and where they might need to shift.

I look at each photographer's methods to understand the logic behind their decisions. How do they negotiate access, how do they treat consent, how do they edit, what do they believe their images should do and where they place their own emotions.

4.1 *On Borrowed Time* by Henrik Malmström

Talking to Henrik Malmström (on November 5th 2025) about *On Borrowed Time* left me with a mix of admiration and also surprise. In this project he photographs and follows his own sister, who will later die of cancer. His work shows how carefully you have to approach illness, especially when it's someone you love, but the way he talked about it was different from what I expected. He spoke with this calm, almost understated tone, not dismissive, but definitely downplaying the emotional and ethical weight in a way I'm not used to. For him, professionalism sits very high on the list. Higher than what I would instinctively describe as care. Not in a cold way, just different than me. And hearing that was good for me. It made me realize that distance isn't the enemy; it can actually be a tool.

He said the phrase: "one foot in and one foot out." Being her brother gave him natural access, he didn't need to negotiate emotional space the way you do with strangers. Because of that, he felt he could work intuitively, knowing when something was okay or not. That's where

his 'downplaying' came through: he made it sound almost easy. "You can always take the photo and decide later whether to use it," he said, as if the moment of photographing doesn't affect the person in front of the lens. For me, that's counter intuitive. I take much more weight to the emotional impact of the shutter itself. But with his sister, he already knew the limits. The relationship carried a kind of built-in consent that you only have with someone very close.

Still, his focus on professionalism was striking. He said he doesn't get too emotionally involved when working, that he observes and participates at the same time. That balance gave the project its tone: intimate but never sentimental, close but never indulgent. He talked about dignity as something you construct in the edit, not only in the moment. He photographed freely and then decided afterwards what belonged in the story. He showed the work to friends and family, letting them also choose images. For him, care wasn't the softness of the moment but the precision of choosing what to show.

What stood out to me is how he reflected on the project years later. He calls it naïve and experimental, not in a negative way but as a recognition of his young age back then. Publishing the book became almost purely professional. He said he couldn't look at it for years because all he saw were mistakes. Yet the emotional honesty is still there, just understated. He even said the project helped him process his emotions, while also insisting that photography shouldn't be used solemnly to process emotion. That contradiction tells so much that the work was both a refuge and a responsibility.

What I take from this is that care doesn't always look like what I think it should. Henrik's version of care is tied to clarity, distance and honesty. It is about not making the images about himself, not turning his sister into a symbol, not over-romanticizing vulnerability. My approach is different: I feel more responsibility in the moment of photographing itself and I tend to place emotional sensitivity before professionalism. But talking to him shows me that perhaps those two don't have to be in conflict. You can create space and you can protect yourself a little. You can let the work breathe without losing respect for the person in front of you.

For my own graduation project this conversation was grounding. It reminded me that care is not just empathy (again, just like the theoretical chapter showed me). It's a set of decisions across the whole process: when you photograph, how you frame, what you edit out and how you invite others into the work. And it also reminded me that I don't have to carry all the emotion myself. Distance can be a form of care too. It keeps things honest, focused and safe for both sides.

What I hope to take forward is a combination of the two. His clarity

and distance and my sensitivity and awareness. I want to give the children I photograph the chance to be seen as they are: not through illness, pity or spectacle, but through presence, attention and respect. A kind of care you practice.

4.2 The general practice of Reinier van der Lingen

Reinier van der Lingen is a Dutch photographer who works with the theme of illness and the topic of the hospital in a lot of his photographic work. His work looks quite different than mine. He is someone with a lot of experience of photographing in this field and therefore I feel like his input could be useful to me.



What struck me first in Reinier's written answers to my questions is how grounded in reality his thinking is. He doesn't hide behind big theoretical language. His ideas come from years of witnessing people at their most fragile, long before he ever became a photographer as an ambulance driver. You feel that in a lot of the things he says. His ethical sense didn't come from books but from working in the ambulance for two decades.



His relationship to ethics is almost the opposite of how we usually talk about ethical photography. He rejects the category in general. For him, ethics isn't a fixed checklist but something that shifts with society (and society has shifted a lot). He names social media as one of the reasons our sense of what is acceptable has narrowed down and hardened. But he doesn't think that change is a bad thing; he just acknowledges the reality he works in.



What does stay constant for him is sincerity. That word returns over and over. Honesty towards the person in front of the camera, honesty about what you want to do, honesty even when you don't fully know yet where the project is going.

There's also something interesting in how he talks about photographing anything and everything. He and Henrik share this idea: if you can see it, you can photograph it. I can't help wondering whether this confidence is something generational or gendered. Or maybe it comes from having spent so many years in emergency work, where the body is simply a fact. With Reinier, it feels less macho than it sounds at first with Henrik. He tells it from a place of clarity rather than 'macho-ness'. His point is not photograph

everything because you can, but photograph everything you believe should be seen and then place your own ethical principles next to it. In other words: the image is allowed, the decision is yours.

I also keep circling back to one sentence because it opens a strange contradiction in his practice: "I tell the stories because I think they need to be told. And whether that creates more or less understanding towards the other side isn't important to me." I find it a bold statement, but it raises (a for me) obvious question: if the goal isn't understanding then what is the story for? He answers this when he talks about his other projects. He sees himself less as a storyteller and more as someone presenting an opinion. He isn't making work to negotiate anything between the patient and audience. He makes work because the encounter moved him, irritated him or stayed stuck somewhere in his mind. The viewer is invited in but the viewer is not the target.



Despite that, his work does slip naturally into a kind of care. When he talks about photography as recognition, that someone's experience is real and matters, it lands in a very human way. He sees photography as a way to give form to something people already carry with them. For the subject, it's validation. For the viewer, it can be understanding or simply the comfort of recognizing themselves in someone else's story. I share this thought. This is where his thinking has the most overlap with my own. In the idea that representation can be a form of care.



His position on visibility versus protection is also blunt in a way I appreciate: "I don't think anything should be hidden. Maybe not everything needs to be shown right now, but eventually there will be a reason." It's almost a temporary ethic, where he uses timing as a form of responsibility. Another thing that stands out is how he talks about truth. He *doesn't* romanticize documentary precision: the moment you press the shutter, the truth is already gone. What remains is your choice, your perspective, your 1/60th of a second.



(Malmström, 2010a)

What I take from his answers for my own practice is that ethical tensions don't need to be resolved before taking the image. They need to be acknowledged and carried before deciding whether the image should enter the world. And that care is something you build into the whole process, not something you add at the end.

4.3 Frida Forever by Frida Lisa Carstensen Jersø

Re-reading Frida's answers after our interview on November 20th 2025, made me realize how different self-portrait work is from photographing other people. Her project Frida Forever grew out of being stuck in hospital for a long time. She says she was in treatment for a year and a half and realized fast that the only thing she could do to hold herself in that time was to make pictures.

Frida didn't start with a neutral plan or a distant ethical checklist: she started because she needed to do it. From that urgency came strong decisions, she knew from the beginning that the book would be public, she wanted it to be seen and she wanted to show the messy, ugly, intimate truths of being sick. The project consists of pre-thought of main images but also many moments she refused to show. That tension between exposure and withholding is central to her approach.

Something she said stood out to me immediately, she rejects the idea that you must photograph everything. She points out that many photographers who say that are photographing other people, often men, and that makes a difference. When you photograph your own body, you are the author, subject and gatekeeper at once. That gives you a different kind of power and responsibility.

She was explicit about wanting the viewer to feel uncomfortable. The book is full-bleed with blood and skin visible. She wanted people to sense the fear. That choice is political. She refuses soft pity. Instead she demands that audiences meet the reality of the female sick body. For my work, this is a strong reminder that representation is an ethical choice, not only what you reveal but how you want your viewer to feel.



Dementia (Van



(Lange, 1936)

Practical features of her process are useful too. Being sick limited the use of her gear. She used what she could carry like small medium format, point-and-shoots, iPhones and asked others (her father, friends) to take pictures when she couldn't. Editing was collaborative: she started herself, then worked with a studio and designers to get distance and finish the book. That collaboration helped her shape a project that was both intimate and public.

Some images she kept private which shows a curatorial instinct that not everything you can photograph should be shown. Yet she did include moments she initially didn't want to show: peeing in bed or a genital image at the gynecologist. Those decisions came from inside her own experience. They were necessary for the story she felt she had to tell. That is a key difference between exploitation and authorship. Frida's choices are rooted in her own knowledge.

A few concrete things I'm taking with me:

Agency matters. Frida's work shows how important it is for the photographed person to have control, even when that person is yourself. For children, that means giving them choices: when to stop, how to pose (or not), whether to see images, who else sees them.

Consent is ongoing. Like Frida, I need to treat consent as something I renew, not a one-time tick box. Short check-ins during shoots, asking permission again before printing or showing, involving parents and medical staff transparently.

Not everything must be visible. Frida shows tough things but also makes clear she withheld many images. For children, I must be especially protective. The camera can make things permanent. My default should be to protect children's boundaries, even if that means losing a strong image when it isn't safe to show.

Use practical limits creatively. Hospital settings will limit time and movement. Frida used small cameras and phones that made her work honest. I can plan lightweight setups that allow quick productions

Make space for the subject's personhood. Frida refused the illness-only frame. My goal should be the same. To photograph children as children first, with personality, play, agency.

Prepare for audience discomfort and choose it consciously! Frida wanted discomfort to force recognition. With children, I must be careful: discomfort that creates empathy can be valuable, but discomfort that objectifies or endangers children is unethical to me.

I am going to ask myself a question constantly: am I making this image for the child or for the viewer? If the answer is for the viewer, I need to rethink it.



Figure 8 (Carstensen Jersø, 2025)

4.4 An informal phone call with Sarah Julia Wong

On September 11th 2025, far before I started working this deep on this research paper, I had an unexpected conversation with Sarah Julia Wong on her project Sophia's Children. There are no recordings or a transcript, but I do have all the notes I took during that conversation. It was a call about her project and that it inspired me to start to do a similar project. I asked her how it went and if she had tips.

One thing she said over and over was: keep journaling. Keep writing, keep asking yourself why you're doing this, keep checking the motives behind your images. According to her, what you photograph is always shaped by your own eyes. By how you're changing, how you're moving through life, what's happening inside you. Your internal world decides how you look at the external one.

She told me Sophia's Children was almost like a deep dive into herself. These were kids who were really sick, many of whom have passed away. She had been invited to photograph them in a way that wasn't clinical or medical, to show something else, something that belonged to them. The children trusted her enough to share big stories, even secrets. She wasn't just the photographer. She became a part of the room.

One thing that I remember well is that she said that the kids didn't want to be photographed as the sick child. They wanted normal things. Boys trying to be tough. Girls wanting to look good in photos. Hearing that helped me realize how quickly illness becomes a visual filter. Her process during the making of the project changed a lot too. She started out using a small camera, trying to be invisible. But then one of the girls told her after five months: "You shouldn't think we walk around here in our pajamas." That moment flipped something. A staff member helped the kids feel like pop stars, more in control of how they were seen.

She kept asking herself: what does this person want? How do they want to be portrayed? It sounds simple, but it's actually the core of the whole thing. She visited every Thursday for months. She'd walk around, talk to whoever was there and photograph the kids who wanted to be photographed. She also made me think about where the work should end up. She was approached later for medical journals, but exhibitions were rare. One big exhibition left her with mixed feelings. Some parents told her: "We want the children to still



Figure 9 (Wong, 2002)

be seen." That tension between honouring someone's memory and protecting their vulnerability is something I might have to face too and that is a big responsibility.

After the book, she burned out, mostly because of the whole production side. Wrong publisher, weird hospital dynamics, the pressure of doing everything right. It's a good reminder that the emotional weight of photographing sick children is one thing, but the practical stress can be just as exhausting.

She said something beautiful about inspiration: let the kids guide you. Their stories, their imagination and their world. Sometimes the perfect picture just doesn't matter, the child does. She loves how imagination can feel magical to kids, but confronting to adults. She talked a lot about autonomy too. That you have to trust your own process, follow the turns the project naturally takes, listen to yourself. She also warned me about journalism: learn from it, but don't get shaped by it. Don't let the agenda of a newspaper become the blueprint for your artistic voice.

The kids she photographed often asked themselves big identity questions: Am I my illness? Who am I now my body doesn't cooperate with me? Those questions sit underneath my own project too. Illness messes with identity. Photography can push that complexity forward or flatten it completely. It's on me to decide which direction my work goes.

5. How do different photographers visually approach the subject of illness and what can their choices teach me?

Photographing illness falls in a space between visibility and vulnerability and care and exposure. The questions surrounding these images: who gets to look? Who gets to speak? How are bodies and suffering represented? - are never neutral. This chapter approaches these questions not through linear argument but through a **visual map**: a conceptual grid that positions a range of photographers and projects according to two dimensions of representation and ethics.

The grid functions as both an analytical and a curatorial tool. It helps me to visualize how artists navigate the ethical tensions of photographing sickness and care. Instead of classifying works as good or bad, the map shows a spectrum of approaches, each defined by different relationships between photographer, subject and viewer. Like this the grid becomes a space to reflect on how ethical and aesthetic choices exist in photographic practice.

The vertical axis, ranging from intimate at the top to detached at the bottom, represents the degree of emotional and relational closeness between photographer and subject. At the intimate end, the photographer's position is empathic or participatory. The subject may be a collaborator, a loved one or even the artist themselves. At the detached end, the photographer has an observational stance, sometimes for scientific, documentary or institutional purposes.

The horizontal axis, spanning from abstract/symbolic on the left to realistic/clinical on the right, captures the visual strategies used to represent illness. The abstract/symbolic side includes metaphorical or performative responses to illness. The realistic/clinical side emphasizes factuality and direct representation. By placing these two axes together, the grid reveals a range of photographic ethics and aesthetics together.

When selecting the projects for this grid, I focused on photographic work that deals with physical illness in a direct way. Portraits, documentary approaches, long-term collaborations and self-representation all felt needed. The selection is also influenced by my own preferences as a photographer, particularly my interest in portraiture and direct, human-centered approaches. I left out projects that deal primarily with mental health, not because they are less important, but because they operate within different representational traditions. This difference partly comes from visibility: physical illness

can often be seen in the body, while mental illness is less visible and therefore requires more indirect or symbolic forms of representation. As a result, the visual language and ethical questions in these practices can differ quite a lot. What ties these chosen works together is that they all work with the question: how do you show a body that is struggling and still treat it with dignity?

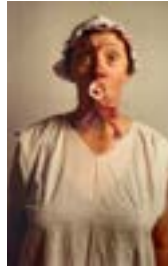
This grid helps me understand how different photographers navigate this question through both form and (personal) position. By placing these projects along the axes of intimate-detached and abstract-realistic, I can see the spectrum of strategies that exist. What I hope to gain is a clearer sense of how visual choices shape the emotional and ethical tone of the work. In the end this mapping gives me a way to articulate where my own work currently sits and where it might grow.

5.1 Annotations for each project on the Grid

Jo Spence – *The picture of health*

Jo Spence photographs her own body while navigating cancer but she does so through constructed images, performance and symbolism. The intimacy comes from the self representation, the abstraction comes from how she uses props, staging and visual metaphors to talk about illness and power in the medical world.

Figure 10 (Spence, 1984)



LaToya Ruby Frazier – *The Notion of Family*

Her images are honest and direct, almost emotionally raw. They're intimate because she photographs family and community from within, but also very realistic because she doesn't romanticize illness or environmental harm.

Figure 11 (Frazier, 2002)



Henrik Malmstrom – *on borrowed time*

A very realistic project in which he shows his sisters journey with cancer in an intimate and fragile way. It is emotionally heavy yet the images are quietly composed without any dramatization.

Figure 12 (Malmström, 2010)



Hannah Wilke – *Intra Venus*

Highly intimate self-portraits where she uses her own body as a symbol of illness, beauty, and decay during cancer treatment. I find the work direct and confrontational. Super personal because she places her body in the centre of the project.

Figure 13 (Wilke, 1992)



Sarah Julia Wong – *Sophia's Children*

Follows children through illness with sensitive imagery, emotionally close but a bit commercial as this is work that is made in commission of the hospital itself. I find she abstracts the children's experiences just enough to avoid clinical distance but to remain inside their world.

Figure 9 (Wong, 2002)

Marijn Fidder – *Stoute cellen*

Another very documentary project where Fidder comes very close to these children, their family and their lives. I think for me personally, this type of photography takes away from the personal part, as it almost seems commercial or commissioned. Yet, you can see she is an insider with these families, which is very special.

Figure 14 (Fidder, 2019)



Miikka Pirinen – *The rare*

Also a more documentary type project that is very good at showing a wide range of angles on the topic and lives of these children. It has more of a realistic tone, while still carrying warmth and closeness between the photographer.

Figure 15 (Pirinen, n.d.)



Frida Jersø – *Frida Forever*

Frida shows a real patient experience in a clinical setting. It is visually very pleasant to look at but still very direct. It is personal because she not only focusses on the hospital experience, but also on being a young woman in this situation.

Figure 8 (Carstensen Jersø, 2025)



Huub van der Put – *The Mind is a Muscle*

In this project Huub asks different photographers to portray him as his ALS progresses, which I find a total different method than all other projects in here. These people all have a different connection to him, but I find it a very new and brave approach.

Figure 16 (Van der Put & Bruessing, 2011)



Nicholas Nixon – *People with AIDS*

Documentary portraits that are deeply humane and intimate, portraying serious illness with a realistic approach. The closeness he build with the people in front of his lens pull this work upward on the intimacy axis.

Figure 17 (Nixon, 1988)



Peter Granser – *Alzheimer*

Intimate portraits capturing cognitive decline and to me it shows very well this vulnerable state that comes with this. It is very observational but also gentle.

Figure 18 (Granser, 2001)



Laila Abril – *The Epilogue*

Symbolic exploration of consequences of societal neglect. It examines grief and loss. It is a very visual storytelling project that is handled with a lot of care. Because of the archive work it far on the abstract side. I can imagine she must've worked on it as a researcher.

Figure 19 (Abril, 2014)



Geert Broertjes – *Inside Room 8*

This project sits as one of the few close to the abstraction side. In this project Geert develops his images with his own pee, pee that is contaminated with chemo. The images distort and discolor. It is personal because he portrays himself, yet a lot of the images show a distance.

Figure 20 (Broertjes & Bronsgeest, 2022)

Philip Toledano – *Days with my Father*

A realistic and tender documentation of his father, which makes it very personal in my eyes. It is intimate but also very structured and well thought off.

Figure 21 (Toledano, n.d.)



Celine Marchbank – *Tulip*

This is a very clear documentary like photo project. The intimacy comes from the mother- daughter bond, yet the images themselves to me seem very observational and factual.

Figure 22 (Marchbank, 2016)



Reinier van der Lingen – *It Could Have Been You If It Hadn't Been Me*

Personal narrative of a woman with cancer. I believe there is a personal bond, yet to me the execution doesn't really show that. It is very factual with lab results and straight- to- the point portraits. That is not bad though, you can't escape the illness and he doesn't beat around the bush with it.

Figure 23 (Van der Lingen, 2012)



Maja Daniels & Jill Mueller – *See Me Through This*

A personal story of illness which has been abstracted by adding yarn in the images. It blends portraiture with symbolic gestures.

Figure 24 (Mueller & Daniels, 2014)



Ruth Adams – *Unremarkable*

Photographs illness and aging in a calm way that seems very day-to-day like to me. The presentation is different than a lot of the projects mentioned. The work doesn't really demand your attention but lets you take your time to look over it. It is very mundane to me, in a good way.

Figure 25 (Adams, 2004)



Kerry Mansfield – *Aftermath*

An emotional present project which is abstracted for the narrative effect. It is personal but also quiet somehow. I find it less raw than Wilke and less documentary than Nixon but still very grounded in this lived experience.

Figure 26 (Mansfield, n.d.)



Alejandro Kirchuk – *Never Let You Go*

Combines personal engagement with his parents and symbolic gestures. It is a personal story that is told with care through these gestures, objects and symbolism. The intimacy comes from being inside his family, the abstraction from the visual language he uses to express an emotional weight.

Figure 27 (Kirchuk, n.d.)



Thilde Jensen – *The Canaries*

The story and the portraits are a real life thing, yet these images have some sort of otherworld feel to me. I think this is because of the use of light and conceptual approach, while we see real bodies and real lives.

Figure 28 (Jensen, 2013)



Koji Takiguchi – *Sou*

Portraits of aging and illness of his family in law. It is a stylized project but still human, it is not really symbolical and not fully clinical.

Figure 29 (Takiguchi, 2014)

Jim Reed – *Working Memory*

Cognitive and neuroimaging project that I find realistic and clinical but also a bit conceptual due to the publication it is in. I find it observational yet deep.

Figure 30 (Reed, 2012)



Matthew Monteith – *Hotel Dieu*

Realistic hospital documentation, one of the few that I see as detached and clinical. It is straightforward hospital documentation and the people that visit. It seems like they're short interactions.

Figure 31 (Monteith, n.d.)



5.3 Findings of the grid

Looking at the grid as a whole, one of the first things that stands out is that most of the projects are towards the top. This positioning suggests a focus on ethical awareness and careful handling of the subjects. The higher placement reflects work that is conscious of the power dynamics that automatically comes with photographing people, especially those in sensitive or intimate situations. They show an intention to prioritize the dignity of the subject.

The grid also shows something about my own interests and choices of projects that I put into this grid. The projects I gravitate toward lean toward intimacy, empathy and relational depth. I am drawn to photographers who take the time to understand their subjects and convey complexity without sensationalizing. The clustering toward the top indicates that my own practice is inspired by an interest in ethical representation. I am less interested in spectacle or purely aesthetic experimentation and more invested in work that shows some form of care.

At the same time, the variety in approaches across the horizontal grid shows that this care can take many forms. The grid makes the balance visible between personal vision and responsibility toward the people being photographed. It reminds me that as a photographer, choosing projects isn't just about what visually intrigues me but that it is also about the ethical stance I bring to my work and the kind of relationships I want to build with those I photograph.

6. Conclusion and findings

6.1 What principles of care can guide future photographic practices on illness?

Looking at all the work I've studied for this research, it becomes clear to me that photographing illness is never just about the body. It's about the space between photographer and subject. It is about trust, tension, uncertainty and sometimes the stubbornness to keep seeing someone as more than their diagnosis. Every photographer I looked at makes their own choices about that space and those choices say a lot about how we represent vulnerability.

What stood out to me is how different the approaches can be, even when the subject is similar. Some photographers turn illness into something almost invisible, like **Celine Marchbank**, letting it exist quietly in the background. Others, like Frida Lisa Carstensen Jersø, confront the viewer with the physical and emotional reality. But in all cases, the photographer has to negotiate: when do you step forward and when do you step back? How do you show someone's reality without claiming it? And how do you avoid falling into the clichés that illness often seems to attract?

Across the projects I analyzed, I kept noticing the same questions coming back. Who has control in the moment of the photograph? Who gets to decide what is shown? And how do you deal with the fact that you, as the photographer, probably might not fully understand what the other person is going through? These decisions decide whether the image feels honest or staged or respectful or invasive.

From studying these photographers, I learned that vulnerability isn't something you capture. It's something people give you, if the situation feels safe enough. That means the ethical part is not only about what ends up in the frame but in my opinion also about what happens before and after the shutter clicks. And it also means that care in photography doesn't look like softness, which was my main focus before this research, sometimes it looks like clarity, boundaries, slowness or simply shutting up and letting the other person speak.

A few things became very clear, or I was reminded of again, throughout this research:

A photograph of illness is never neutral.

The photographer's presence, decisions and distance from the subject all shape the meaning. Pretending otherwise is naïve!

Illness carries its own visual stereotypes.

If you're not careful you repeat them without noticing and you show only the fragile patient, the sad close-up and the medical gaze. Breaking them requires intention.

Care is not a style, it's a practice.

It shows in logistics, communication, how you pace yourself and the agreement you build together.

Empowerment isn't given by the photographer.

It happens when the subject feels seen on their own terms, not yours.

Representation of illness is relational.

The image is shaped by the dynamic between two people, not just by technical or aesthetic choices.

6.2 What this means for my own practice

Working through all this material has made me look more critically at my own way of photographing people who are ill. I recognize how quick I could slip into wanting to explain their situation visually. But I've been reminded of again that my responsibility is not to explain it's to listen, to show up honestly, to create space where the person can exist without being reduced to their condition. Because that is exactly what I aim to do.

It also made me more aware of my own position: I'm always an outsider to the experience of illness of someone else, even though I have experience with it myself. And instead of pretending I'm not, I need to acknowledge that distance and work with it. I don't have to understand exactly what someone feels in their body to photograph them with care. I just have to stay aware of the power I have in the moment and make choices that don't take anything away from them.

In my own projects (if it's working with sick children, undocumented people, or anyone navigating a vulnerable situation) this research taught me to move slower, ask better (!) questions and let the person guide the direction more than I usually would. The image doesn't have to be dramatic to be meaningful. It doesn't have to reveal everything. In the end, this paper is both preparation and reflection. It gives me a foundation for my graduation project and for my future work with people in vulnerable situations. And it shows a way of photographing illness that is not about showing everything, but about showing someone with clarity, honesty and care.

Abstract

This research explores the ethics of photographing people living with illness, focusing on the relationship between photographer and subject. It asks how care, trust, representation and power shape the act of making portraits in vulnerable situations and how photographers can avoid reducing individuals to their diagnosis.

The study combines theoretical research on ethics and care, semi-structured interviews with photographers, and visual analysis of photographic projects. Across these approaches, the research shows that images of illness are never neutral but shaped by the interaction between photographer and subject. It highlights how easily photography can reproduce stereotypes and it argues that ethical practice is not only about rules but about attentiveness, communication and working with care.

The findings suggest that photographing illness requires a relational approach in which the subject's experience and agency remain central. Rather than explaining or defining someone through an image, photography can create space for a more complex and human presence.

List of sources

- Aristotle, W., D. (1999). *Nicomachean ethics*. Batoche Books. <https://history-of-economichthought.mcmaster.ca/aristotle/Ethics.pdf>
- Azoulay, A., Ewald, W., Raiford, L., & Wexler, L. (2023). *Collaboration: A potential history of photography*.
- Carstensen Jersø, F. (2025, February 7). *FRIDA FOREVER :: Fridalisa.dk*. Frida Lisa. <https://www.fridalisa.dk/frida-forever/>. Consulted November 2025
- Evers, H. J. (2012). *Media-ethiek: morele dilemma's in journalistiek, communicatie en reclame*.
- Kant, I. (2012). *Groundwork of the metaphysics of morals* (Jens Timmermann, Ed.; Mary Gregor, Trans.). Cambridge University Press. https://assets.cambridge.org/97811070/08519/frontmatter/9781107008519_frontmatter.pdf Consulted October 2025
- Malmström, H. (2010, March). *Henrik Malmström. On Borrowed Time*. <https://www.henrikmalmstrom.com/works/on-borrowed-time/>
- Mill, J. S. & THE FLOATING PRESS. (1879). *Utilitarianism* [Book]. <https://www.utilitarianism.com/jsmill-utilitarianism.pdf>
- Mitchell, W. J. T. (2006). *What Do Pictures Want?: The Lives and Loves of Images*. University of Chicago Press.
- Puig De La Bellacasa, M. (2017). *Matter of Care: Speculative Ethics in More than Human Worlds* [PDF]. University of Minnesota Press. [https://syllabus.pirate.care/library/Maria%20Puig%20de%20La%20Bellacasa/Matters%20of%20Care%20\(171\)/Matters%20of%20Care%20-%20Maria%20Puig%20de%20La%20Bellacasa.pdf](https://syllabus.pirate.care/library/Maria%20Puig%20de%20La%20Bellacasa/Matters%20of%20Care%20(171)/Matters%20of%20Care%20-%20Maria%20Puig%20de%20La%20Bellacasa.pdf)
- Rovers, S. (2020). *How to become a socially engaged photographer* [Thesis; E-book]. Royal Academy of Arts The Hague.
- Schumman, A. (2008). *Life Before Death. Foam Magazine #17 / Portrait?*, 17, 135–154.
- Sontag, S. (2004). *Regarding the pain of others*. Penguin Books, Limited (UK).
- Sontag, S. (2008). *On photography*. Penguin Classics.
- Tammi, M. (2017). *Sick photography: representations of sickness in art photography* [Thesis]. Aalto University.
- Tronto Joan. (1993). *Moral Boundaries* [PDF]. Routledge. [https://syllabus.pirate.care/library/Joan%20C.%20Tronto/Moral%20Boundaries_%20A%20Political%20Argument%20for%20an%20Ethic%20of%20Care%20\(416\)/Moral%20Boundaries_%20A%20Political%20Argument%20for%20-%20Joan%20C.%20Tronto.pdf](https://syllabus.pirate.care/library/Joan%20C.%20Tronto/Moral%20Boundaries_%20A%20Political%20Argument%20for%20an%20Ethic%20of%20Care%20(416)/Moral%20Boundaries_%20A%20Political%20Argument%20for%20-%20Joan%20C.%20Tronto.pdf)
- Van der Lingen, R. (n.d.). *Reinier van der Lingen*. <http://reiniervanderlingen.nl/>. Consulted November 2025
- Verhofstadt, D. (2019). *Media en ethiek 2019*.
- Webb Marilyn, Livingston Jane, & Brookman, P. (1996). *Hospice: a photographic inquiry* (1st ed.). Bulfinch Press.
- Wong, S., Goudappel, A., & Kleijwegt, M. (2002). *Sophia's Children. DUO/DUO*.

List of figures

Figure 19: Abril, L. (2014). Cover of the book. The Epilogue - Laia Abril. <https://www.laiaabril.com/project/the-epilogue/>

Figure 15: Adams, R. (2004). Unremarkable. Unremarkable - Ruth Adams. <https://www.ruthadamsphotography.com/unremarkable>

Figure 20: Broertjes, G., & Bronsgeest, L. (2022). Outside room 8. Geert Broertjes. <https://geertbroertjes.com/outsideroom8>

Figure 8: Carstensen Jersø, F. L. (2025). Selfportrait. Frida Lisa. <https://www.fridalisa.dk/frida-forever/>

Figure 14: Fidder, M. (2019). Daley. Zilveren Camera. <https://www.zilverencamera.nl/jaargang/2019-2/1e-prijs-documentair-nationaal-2019/>

Figure 11: Frazier, L. R. (2002). Ms. Frazier's mother in a Braddock Hospital bed. New York Times. <https://archive.nytimes.com/lens.blogs.nytimes.com/2014/10/14/latoya-ruby-fraziers-notion-of-family/>

Figure 18: Granser, P. (2001). Portrait 19. Granser. <http://granser.de/alzheimer.html>

Figure 28: Jensen, T. (2013). The Canaries. The Canaries. <https://thildejensen.com/statement.html>

Figure 27: Kirchuk, A. (n.d.). Never let you go. Alejandro Kirchuk. <https://alejandrokirchuk.com/never-let-you-go/>

Figure 1: Lange, D. (1936). Migrant Mother. MOMA. <https://www.moma.org/collection/works/50989>

Figure 5: Malmström, H. (2010a). On Borrowed Time. Dummy #33 Familie. https://henrikmalmstrom.com/downloads/084_093_Dummy33_Schwester.pdf

Figure 12: Malmström, H. (2010b). Selfportrait with Maaija. Henrik Malmstrom. <https://www.henrikmalmstrom.com/works/on-borrowed-time/>

Figure 26: Mansfield, K. (n.d.). Aftermath. Aftermath Series. <https://www.ker-rymansfield.com/aftermath>

Figure 22: Marchbank, C. (2016). Mother in mirror. Book: Tulip. <https://www.celinemarchbank.com/work/tulip>

Figure 31: Monteith, M. (n.d.). Woman on hospital bench. Hôtel Dieu - Matthew Monteith. <https://www.matthewmonteith.com/hotel-dieu>

Figure 24: Mueller, J., & Daniels, M. (2014). Medical photograph being taken before reconstructive surgery. Financial Times. <https://www.ft.com/content/c0aad8ea-a8ff-11e5-9700-2b669a5aeb83>

Figure 17: Nixon, N. (1988). Tom Moran, Boston. ICA Boston. <https://www.icaboston.org/art/nicholas-nixon/tom-moran-boston-january-1988-series-people-aids-0/>

Figure 15: Pirinen, M. (n.d.). No title. Photographer Miikka Pirinen. <https://www.miikkapirinen.com/rare>

Figure 30: Reed, J. (2012). One spread in the book. Photo Eye Bookstore. <https://www.photoeye.com/bookstore/citation/ZF267>

Figure 2: Riis, J. (1872). The Other Half. FOAM. <https://www.foam.org/nl/events/jacob-riis>

Figure 10: Spence, J. (1984). Photo therapy: infantilization. Hyman Collection. <https://hymancollection.org/artworks/1916-jo-spence-photo-therapy-infantaliza->

[tion-from-the-picture-of-health-1984/](https://www.foam.org/nl/events/jacob-riis)

Figure 29: Takiguchi, K. (2014). Wife with mother in law. Shashasha Photography in Art & Books. <https://www.shashasha.co/en/book/sou>

Figure 21: Toledano, P. (n.d.). My father often tells me he wants to die. Days With My Father. <https://mrtoledano.com/photo/days-with-my-father/thumbnails/>

Figure 7: Van der Lingen, R. (2011a). 112 afbeelding 4. Reinier Van Der Lingen. <http://reiniervanderlingen.nl/112-4/>

Figure 6: Van der Lingen, R. (2011b). It Could. Reinier Van Der Lingen. <http://reiniervanderlingen.nl/it-could/>

Figure 23: Van Der Lingen, R. (2012b). Portret. De Correspondent. <https://decorrespondent.nl/2341/factcheck-kanker-is-in-65-procent-van-de-gevallen-gewoon-pech-hebben/6a7365ac-31de-04f5-1612-ebc091676e18>

Figure 5: Van der Lingen, R. (2014). Verlangen. Reinier Van Der Lingen. <http://reiniervanderlingen.nl/people/>

Figure 4: Van der Lingen, R. (2024). Dementia. Reinier Van Der Lingen. <http://reiniervanderlingen.nl/people/>

Figure 16: Van der Put, H., & Bruessing, A. (2011). Huub van der Put. Amsterdam UMC. <https://vbcn.nl/nl/collecties/amsterdam-umc/messages/the-mind-is-a-muscle-huub-van-der-put>

Figure 13: Wilke, H. (1992). Intra Venus series no.4. Ronald Feldman Gallery. <https://feldmangallery.com/exhibition/164-intra-venus-wilke-1-8-2-19-1994>

Figure 9: Wong, S. J. (2002). Sophia's Children. Sarah Wong. <https://www.sarahwong.com/healthcare>

Transcripts

Interview with Henrik Malmström on his photographic series

On Borrowed Time

L: How did On Borrowed Time begin for you? Was it a conscious decision to photograph your sister's illness or did it emerge more intuitively from being close to her?

H: I started with photography by chance. I was studying engineering and got interested in photography, eventually working for a newspaper. My sister had been ill for a long time, about ten years, and my mother had also died the year before from cancer. When my sister got ill again, you know, the cancer comes and goes, she knew she was going to die. At that point, I was very interested in documentary photography. It was a conscious decision to make a record of it.

L: How did your relationship with your sister shape the photographs, both emotionally and visually?

H: Instead of going to someone's home and having to strike up a conversation, this was easy because of our close relationship. There was natural access. I tried to keep one foot in and one foot out, to stay close but also maintain some distance. Visually, I tried to find new angles. The bond didn't make a huge difference in that sense. She obviously saw me photographing and was aware of it. I can't remember if she knew I was going to do something with the work or, well, she knew in the end, because I sent her the images, and I even won a prize for them. She was happy for me.

H: I remember my dad wasn't too happy at first. "Wow, what are you doing?" But when the book came out, he said, "that was the best thing you did." The rest of the family eventually felt the same. She felt okay about it; I tried to respect her, to not define her as just this ill person. My other sister and her friends also reminded me to respect her as a person.

L: How do you do that?

H: I guess by finding dignity in moments, not only the bad parts, and by showing their personality, their humanity.

L: Did you discuss the project with her? How did she feel about being photographed during her illness?

H: She knew I was photographing her and felt okay about it. I tried to be respectful, not to make her feel objectified or reduced to the illness.

L: How did you navigate the fine line between being a brother and being a photographer? Did those roles ever conflict?

H: I don't think they conflicted. It was good for me, I could observe and also be part of it. I felt comfortable in that role. That balance has followed me until now. You can always be two things at the same time, and I don't get too emotionally involved when I'm working on something.

L: Were there moments when you chose not to photograph, and if so, why?

H: There were two explicit moments. I learned this rule: you can always take the photo, you can decide later whether to use it or not. There were also photos I missed, moments when I was too slow, and I regret those more than the ones I didn't take.

L: How did you think about consent, dignity, and respect in moments when your sister was most vulnerable?

H: You can always take the photo and then just not show it. It's intuitive, you know when it's not the right moment. But being family, I could do it more naturally. When you're working as a photojournalist, the camera sound goes off, it becomes more of a technical act and choice to make the picture or not

L: In situations where your subject is family, does the sense of ethical responsibility feel different than in a professional context?

H: It shouldn't be different; it should always be the same. Maybe you can push the limits more, or maybe less, but you should always be professional. After this, I started photographing in hospices, to see if it was something I wanted to continue, but it wasn't. I realized I was trying to replicate something I had already done. It's a hard environment. My older sister is a hospice doctor, she was like, "oof, that is hard." I realized I was trying to copy myself.

L: How did you ensure that the images would not become voyeuristic or exploitative, but instead communicate care and love?

H: That happens mostly in the edit. You take the images first and later decide what you want to communicate. Some of the images could seem voyeuristic if it hadn't been my sister. I remember at that time I was just starting to study and was very interested in photographing people. There was a lot of discussion about voyeurism, but I wasn't too interested in that debate. I think if you care for the person, it's not voyeuristic.

L: When editing or publishing the work, how did you decide what to include or leave out?

H: I showed the work to a lot of people, her friends, family and they would say yes or no to certain images. Maybe some images I wouldn't include today. I tried to respect them all while still telling a story. Some decisions you make with others, some alone.

L: You have to have one foot in and one foot out when editing. Really look at it and think: is it worth it or not? How did your choice of distance, framing, or focus express your relationship to your sister's experience?

H: It was the first larger project I ever photographed, so I just experimented. Nowadays I always work in a similar way, but back then I was playing around more. Those were conscious choices: trying things, hiding things through framing. It was naïve and experimental, seeing what could work.

L: Did the process of photographing help you process your own emotions, or did it make the experience more complex?

H: When my mother died, I was relieved. She had been sick for twenty years. With my sister, I used the process to work through my emotions too. Publishing helped me move on.

L: What was it like to live with the photographs after her death, to look at them again, to edit them, to publish them?

H: It was totally professional, no emotion when I published it. It was the first book I made. When I printed it, I could only see the mistakes. I couldn't look at it for five or six years because all I saw were the errors. Maybe now, fifteen years later, I can say it's okay. It's for people to like. With the rest of my work, I'm not interested in looking back. I move forward. It's for others now. It takes time; I was young then.

L: How old were you?

H: The book was published in 2010; I photographed it in 2008. I was 25 when photographing, 27 when publishing. I had no education in art, but I have a lot of artist friends. I look at them and admire them. Maybe it's imposter syndrome, but I always feel like I should know more.

L: Did your understanding of the project or your sister's story change through that process?

H: It wasn't easy. When I started researching for the book, I had no idea what that world was. I never really knew what I wanted to do, but it was clear that this was a linear project, a beginning-to-end story, not elliptical. That didn't change. What did change was my understanding of the images and what to use over the years I spent looking for funding. The concept was always clear: no experimental storytelling. My understanding of photography itself changed during the bookmaking process, as I looked at other books.

L: How did audiences respond to *On Borrowed Time*, and how did you feel about others seeing something so personal?

H: People close to me liked it. I tried to get editorials interested, but no one was. They thought it was too personal. I understand that, even though it's very universal.

So I self-published. I managed to sell the copies, and the response was good. But I realized I wasn't doing something new. This had been done many times. At that time, photobooks weren't as popular; it was still more about fashion or "Vogue" photography.

L: Has this project changed the way you think about photographing vulnerability or illness?

H: Yeah, I think so. I haven't photographed much vulnerability since, but I am drawn to the margins of society. I don't get too emotionally involved; I keep a professional distance. It's not that I don't care or listen but I'm there to get an image. It's a mix, a kind of play. It definitely taught me something.

L: If you were to make the project again today, would you approach it differently?

H: For sure, though I don't know exactly how. I'd be more precise. Nowadays I choose a specific format or approach for each project. Back then I chose black-and-white film because I thought that's what you were supposed to do. I have more knowledge now.

L: Do you believe photography can offer a form of care, either for the person being photographed or for the photographer?

H: For me, it was a kind of refuge. You can hide behind it, it gives you something to do. You have to put yourself in the other person's shoes and think about what's comfortable for them. If they get used to you being there, maybe it can be a form of care, though I didn't ask her. If I were ill and someone came to photograph me, I wouldn't care, or maybe I'd appreciate having someone to talk to. In that way, it could be nice.

L: What do you think photography can reveal about illness that words cannot?

H: It can show things words cannot say. I believe that, even if I don't know if I can say anything particularly smart about it.

L: Looking back, do you think *On Borrowed Time* was a way to hold onto your sister or a way to let her go?

H: It was a way to let her go, more than to hold on. Though at the same time, it remains a memory. For my dad, it's a way to hold on. For me, to let go.

L: What would you want other photographers to understand about photographing someone they love who is ill?

H: I don't know, that's a good question. Maybe it goes back to understanding the form of care they have for the person. , should they like ask if it is okay... I am not sure if I understand the question.

L: Maybe I can rephrase. What have you learned while photographing someone who was ill?

H: Photography-wise, I learned not to become too emotionally invested, in a way, not to process it through the work. Personally, I learned not to get too involved, to stay professional. If you do it for yourself, that's one thing, but if you also want to show it to others, it shouldn't be too cliché or too personal. You want people to be able to look at it: not too romantic, not too sad, not too obvious. Try to keep it real, not cliché. If I were to approach it again, I'd probably be more clinical, colder, more distant. That's how I work now. But then again, my dad is getting old now, starting to get dementia. I live in Buenos Aires, and I'm thinking of going back to film him, not photograph, but film. Not to make a work about old people, but just to have something for when he dies. I'm interested in filming and getting very close. It's just an idea. Now I'd be much more aware of how I want to show it and what they might want to see. But you can also just not give a shit, do it anyway, and let people complain.

Interview with Reinier van der Lingen on his general photography practice

L: How did your interest in medical and ethical photography begin?

R: I worked as an ambulance driver between 1999 and 2021. As a result, you encounter many people who have experienced setbacks in life. And you see how they deal with them, or not. How people handle what they go through, or life itself, has always fascinated me.

By the way, I don't know if something like ethical photography exists. I think the ethical aspect of art, and I include photography in that, mainly depends on the society in which it is presented, and on the social and cultural background of the maker.

L: Many of your projects arise in collaboration with hospitals or research institutions. How did those collaborations begin, and how do they influence your work?

R: I only collaborated with an institution for my project 112, namely the ambulance service. And that was only because I needed them. I needed permission to ride along as a photographer.

I started the conversation with a project proposal. In it I wrote down my ideas, my vision, how I wanted to present it, what I needed from them, etc. They had no influence on the work. The only requirement was that I had to stay within a legal framework of asking for and obtaining permission. Within that, I could photograph whatever I wanted. For *It Could Have Been You*, I needed medical data, but I had those requested by Babet, the woman in the photos. After all, they were her records. The photos I made in institutions were all made without any specific agreements.

L: What does ethical photography mean to you personally? And has that meaning changed over the years?

R: As I said, I don't think something like ethical photography exists. What has changed is society. Society now has different ethical norms than 30 or 50 years ago. A society changes, and ethical norms change along with it. I think this is partly due to the increased amount of images in the (social) media. Facebook has broken a lot.

L: When working within a medical context, how do you handle the theme of consent?

R: I have always asked permission from all the people who are part of my photography. For the portraits in *Dementia* and *Genes*, that's obvious, otherwise I couldn't make the portraits. But I always explain what my ideas are. For 112 I had permission from the GGD to photograph the employees during their work. I had to ask all patients separately for permission through a letter and a consent form. I also made a project about children in group 8 of primary school. For that, I had to get permission from all the parents, every single one. The biggest challenge is when you don't yet know exactly where a project will go. Then it's important to describe the project as broadly as possible.

L: How do you balance the clinical or institutional demands of medical documentation with your own artistic vision?

R: My own vision comes first. Except for 3 Months and 112, my work leans more towards the autonomous than the documentary. Even Desire, which has a very documentary character, is not so much about what I record but about what I think of it, my vision of IVF.

Genes, Dementia and It Could Have Been You are mostly autonomous, I think. These projects are research projects in which I investigate how I can visualise my vision. There is also another project, Memories, which continues my thinking about dementia, a kind of follow-up to Dementia.

L: Do you see yourself primarily as an observer, participant, or perhaps a mediator between patient, doctor and audience? And why?

R: I think I'm all of them. In 112, mostly an observer. In 3 Months and Desire, both participant and observer. The latter two are about what we as a family experienced and how we dealt with it. My goal is never to mediate. I tell the stories because I think they need to be told. And whether that creates more or less understanding towards the other side isn't important to me. In the other projects I'm less a storyteller and more someone who presents an opinion, a vision, about what fascinates me.

L: Are there moments when you consciously decide not to photograph? And how do you recognise that boundary?

R: Not really. I think everything can and may be photographed. If people can see it, it can also be photographed and maybe it should be photographed.

L: Medical imagery often borders on voyeurism or objectification. How do you ensure your images maintain the dignity and humanity of the people portrayed?

R: If you are honest and sincere in your motivation, your images will remain that way. So be honest with your subject. Honestly explain why you want to make the images, what images you have in mind, what the goal of the project is. And if you don't yet have that completely clear, which can happen, then be honest about that too. Voyeurism is always about dishonesty, not being sincere, because it makes something feel sneaky.

L: Do you think photography can be a form of care, not only for the person portrayed but also for the viewer?

R: Yes, I do. For the person portrayed it is a form of recognition, that what they experienced matters, that it is not strange or unimportant, that people are interested. For the viewer, it can be a form of recognition too: realising there are more people who have gone through the same thing, perhaps even in the same way. But also simply increased knowledge, making them better able to understand a process or illness.

L: How do you deal with the tension between showing and protecting, between what may be seen and what might be better kept hidden?

R: I don't think anything should be hidden. Maybe not everything needs to be shown right now, but eventually there will be a reason. So photograph everything you believe should be shown, and then place your own ethical principles next to it.

L: Has working in the medical world changed your view of the body, vulnerability or mortality?

R: Yes, definitely. I've become much more aware of the fragility of life. I've also realised that whether you stay healthy is mostly a matter of luck or bad luck. Of course you can try to influence a few things through lifestyle, but in the end it's basically a coin toss.

L: In your work the boundary between documentation and abstraction often blurs. What does that aesthetic distance mean to you? Is it a form of protection or a way to encourage reflection?

R: My older work is more documentary than my newer work. I'm now mainly focused on translating the world, or my view of the world, into images. So less telling, more translating. I notice that I enjoy that more, but also that I can express my ideas better because I no longer have to search for existing images, I can create them myself much more.

L: How do you think about 'truth' within medical imagery, where clinical precision and artistic interpretation meet?

R: There is no "truth." The moment someone presses a button and makes a photo, it becomes the photographer's vision. 1/60 of a second later, reality has already changed and shows more or less than the photographer did. Everything is an interpretation of the maker. And if you're clear about that, it's not a problem.

L: When selecting or exhibiting work, what ethical criteria do you use to decide what will and will not be shown?

R: My own norms and values. And those are shaped by the society and the era in which I grew up. That determines what I want to show and what not.

L: How do you use scale, focus or texture to translate something that normally remains hidden inside the body into a visual language?
I'm a big fan of blur. It creates mystery in images because the viewer has to interpret more.

R: Have you ever encountered resistance from institutions or the public because of the ethical questions your work raises?

R: If you consider confrontation to be an ethical issue, then yes. It Could Have Been You turned out to be very confronting for many people who had dealt with cancer. It reminded them of their own period, or that of someone close to them, and the images brought them back to a time they didn't want to revisit. But otherwise no.

L: What kind of dialogue do you hope your work starts, between art and medicine, or between photographer and audience?

R: The dialogue between photographer (visual artist) and audience. The medical aspect might be my subject, my muse, if you want to call it that, but I am and remain primarily a visual artist communicating with an (interested) audience.

L: Do you see your practice as part of a broader critique of how our society visualises illness and the body?

R: I've never really thought about it that way. I come from a society that looked at physicality differently. Social media didn't exist yet, so there wasn't a flood of images. Women lay topless on the beach without being afraid of ending up in WhatsApp groups.

But my work isn't about that. It withdraws from current norms, I think, because it's about what I see happening in people and what that does to me, what I think of it. Not about what society thinks of it.

L: Has working with images of illness and vulnerability over many years changed your own relationship to health, empathy or mortality?

R: Yes, definitely. I've become much more aware of the fragility of life. And I've realised that whether you stay healthy is mostly a matter of luck or bad luck. Of course you can try to influence some things through lifestyle, but in the end it's a coin toss. Because of that, I've developed more empathy for the people in my images.

L: If you had to name one ethical principle that always guides your work, the line you would never cross, what would it be?

R: Sincerity. Always remain sincere in your intentions and your communication. And be aware of your responsibility toward your subject: they are the vulnerable ones, not you as the photographer/artist.

Interview with Frida Lisa Carstensen Jersø on her photographic project Frida Forever

L: How did the Frida Forever project start?

F: I also have a disability and also have a sickness, illness, so I have dual in this. But when the project started I was at the hospital again. I was at my bachelor degree in photography at that moment, so it was not like new for me to work with myself or sickness or illness or disability. But I was at the hospital for one and a half years during my bachelor, so it was very natural to just keep on taking pictures in that setting. And I was like: I'm a photographer, I take pictures, so let's go. Yeah, I was mainly at the hospital all the time, so there was not a lot to take pictures of other than myself.

L: Would you say that was also a practical choice?

F: Um, also a practical choice, maybe. But it was the only choice I had.

L: Was it also a survival thing?

F: Yeah, I also think it was a survival thing. It was like: I'm a photographer, when I keep on taking pictures and making art, so this is just a situation where I need to take it here. I also find it important for me to do something, still keep on doing things. Also, because I've been working with illness in photography before, it was nothing new. It was just a really visually great setting to be in.

L: Did you always intend for the work to become public, or was it something you made for yourself first?

F: I was hospitalized, and after the first week I was like: I'm gonna make a book about this, with self-portraits and this setting. I've been sick like this before, and I know it's gonna take a year or two before I get out, if I even get out. So I was like: I have to do this, I have to make a book. I think it was like a perfect project for a book. So I started making the book at the hospital.

L: Can you tell me a bit about the disease you have, next to the complications from the fall in 2012?

F: Yeah, I broke my back and I'm in a wheelchair. But the disease is... they don't know why I have it. Maybe it's from the accident, maybe it's not. Nobody knows. But it's like a cellular dysfunction, so I grow a really big piece of skeleton out of muscle and soft tissues. Mainly in my right hip, then down to the knee and a bit up in the stomach. It just spreads.

L: How does it react? For example, if you get really sick, like with a flu?

F: It can react. It's not linear. I haven't had it for like three years, two and a half years.

L: When I look at the images, they feel very personal, but also controlled. How do you balance exposure and authorship?

F: Well, a lot of the main pictures in the book are quite planned. I knew what I wanted, how I wanted it in the book, and what I wanted to be seen. There's also a lot of pictures I don't want anybody to see, or things I will never take pictures of.

Some photographers say "photograph everything" and decide later what to show.

L: But are they taking pictures of themselves or other people?

F: Other people.

Yeah, that's kind of experience. It's not their own body that's exposed, not their own stories. They're exposing other people's stories. Also, the photographers you talk about are male. I also think that makes a difference.

L: As both subject and photographer, how do you balance the role between the one who feels and the one who frames?

F: I want to make art I want to see myself. There aren't a lot of people taking pictures being disabled and sick, taking pictures of themselves. I really want to see other people do that. Most of what I do is because I think it's missing in the scene. There's a lot of people taking pictures of other people being sick and I wanted to embrace my own body. My book and projects are very much to other people and what I am longing to see at galleries and bookshops.

L: How does your own experience influence how you approach photographing in hospitals?

F: You also have the experience yourself and the cross boundaries you've experienced as a hospital patient as a kid. I think you have to have respect for the kids. If you don't have the experience, or you're not a female body, maybe photographers taking pictures of sick people lack respect. I just take pictures of what I feel in the moment.

L: Did photographing yourself during illness change how you perceived your own body?

F: It changes all the time how I feel about it. Using photography as a manifestation is like: I'm here, I'm worth it, I'm worth being in a pretty purple book, being at museums and galleries, even at a fragile moment, maybe dying. It's going to be out there forever. It gives me confidence and gives this body the right to be in fancy places.

L: Did you develop certain rituals or routines in the process?

F: Most of the pictures were taken when I was very scared, maybe of dying. Many pictures in the book show me wearing hospital gowns, during surgery days every third

day. The worse I felt, the more pictures I took. Sometimes I was too weak, but when I felt low, I needed to do this. I used mainly my dad to take pictures when I couldn't do it myself. Friends also helped.

L: How do you handle consent with yourself?

F: I don't really do that. I have a style and way of taking pictures, and I explain that to people or draw a picture. The pictures I take, I can choose to show or not.

L: Did you ever withhold or deliberately include things to provoke the viewer?

F: The book is edited very full bleed, mostly all the time. There's blood and skin and a lot of pain. I wanted the viewer to feel a bit uncomfortable, because it's uncomfortable to be me. For a sick person, seeing blood, scars, needles is common, but for others, it's a lot. I wanted them to feel fear of dying or discomfort.

L: How do you balance vulnerability and control?

F: There is a fine line. One picture in the book shows my vagina because I was in a fertility clinic for radiotherapy. I postponed it, but then I felt it was really important. It's about the female sick body, showing fragility. Another picture shows me peeing in bed because I wasn't allowed to leave. It was over my boundaries, but I needed to show it.

L: Do you see this project as documentary, performative, or a combination?

F: I don't think there's anything performative. It's very true. Some shoots were planned, but mainly, it's graphic work. I am myself, but also the curator of the book. Many things I don't show.

L: What visual choices did you make for the images?

F: Being very sick, I couldn't use big lighting or light measurement. Normally, I shoot on Hasselblad, but it was too heavy. I used lighter medium format cameras, small point-and-shoots, digital cameras, and even iPhones for some pictures. Whatever I could bring around at the hospital.

L: Did you need permission to photograph in the hospital?

F: No, only two places. For the surgery hall, normally no cameras allowed. Because I was there all the time, they allowed it. For radiotherapy, I wasn't allowed to bring a camera, but I took my iPhone. They got mad, but it was worth it.

L: How did photographing over time influence the meaning of the project?

F: Main pictures were from one and a half years at the hospital. I already had a publisher deal while still in treatment. I wanted the book about being sick and nothing else. Then, older vacation pictures gained new meaning in this context. I also took

self-portraits for about a year after. The book shows both sides.

L: How was it to edit the book?

F: I started editing at the hospital myself. A studio later helped with editing and graphic design for over a year. It was a close collaboration. It was professional, which helped me have distance from the work.

L: How did other people react to the book?

F: Close friends and family found it hard but a good way to talk about that time. People who've been sick contacted me to show their work. Many said it was needed from this perspective.

L: Did this project change how you think about photography?

F: I learned a lot about self-manifestation and the power of photography. The book is almost sold out, and it's in homes, apartments, and libraries worldwide. I felt the power of sharing this story. Working afterwards mainly with sculpture has been difficult; I want to work on a book again.

L: Looking back, would you continue the project if something similar happened, or do anything differently?

F: If I get sick again, I would take pictures again. Some pictures I wish I had taken. Mainly, I now want to work on disability. There are things being in a wheelchair, like access to museums and schools. I want to focus more on that.

An informal phone call with Sarah Julia Wong

On September 11th, far before I started working this deep on this research paper, I had an unexpected conversation with Sarah Julia Wong on her project Sophia's Children. There are no recordings or a transcript, but I do have all the notes I took during that conversation. It was a call about her project and that it inspired me to start to do a similar project. I asked her how it went and if she had tips.

Blijf journalen!!

Blijf spiegelen: waarom doe ik dit? Wat jij fotografeert en ziet gaat over jouw ogen

De manier waarop je fotografeert wordt bepaald door hoe jij groeit, hoe je beweging voelt. De beweging in jou bepaald de blik naar buiten.

Sophia's children was een diepe reflectie. De verbinding aan gaan met hele zieke kinderen. De meeste leven niet meer.

Ze is uitgenodigd door een filmmaker en directeur om de kinderen op een andere manier in beeld te brengen. Ze keek anders de wereld in. de kinderen vertelde de grootste geheimen. Ze werd deelgenoot.

De kinderen die zij fotografeert wilden vooral heel gewoon zijn. Cystic fibrose was een afdeling waar ze veel kwam. Jongens zijn wat stoerder, meisjes willen liever op de foto.

Als beeldmaker ging het haar om verdieping in het werk. Een nieuwe laag.

Blijf journalen! Waarom doe ik dit? Laat dit zien in je werk, dit onderscheid jou.

Krantenwerk is inwisselbaar, geeft ervaring en geld.

Eerst kleine camera om ontzichrbaar te zijn, totdat ze bedacht dat dat niks opleverde. Een van de meisjes zei na 5 maanden: je moet niet denken dat wij hier in onze pyjama rondsloffen. Jolande zorgde ee voor dat ze benaderd werd als een popartiest, maar ook zoals ze zelf waren

Wat wil de persoon zelf? Hoe wil jij verbeeld worden? Hoe wil jij gezien worden?

Ze was er vrijwel iedere donderdag. Rondje lopen, en wie er was ging op de foto

Bouw een vertrouwensrelatie op.

Daarna veel benaderd voor medische tijdschriften.

Waar mogen de werken hangen? Waar komen ze tot hun recht? Waar hebben ze betekenis? Wie dienen we hiermee? Maar 1x geexposeerd in Fotofestival Naarden, maar toch met dubbel gevoel.

Wij willen juist dat ze nog gezien worden! Zeiden ouders. Je kan voor mensen een voorpreview geven.

In Radboud UMC hangen er een aantal. En in een boek.

Voor wie? Waar wil je het laten zien? Waarom doe ik dit? Wat draagt dit werk bij? Je mag het ook luchtig houden. Je kan iets ook stuk beredeneren. Maar dit is wel de meest reflectieve manier om je visie te beredeneren.

Burn out na het boek, door het zakelijke/technische deel er na. Via ziekenhuis verkeerde uitgever.

'Zichzelf beter gemediteerd' bij beginnende leukemie.

Laat je inspireren aan de kinderen en hun verhalen. Kon afbreuk doen aan de vorm, maar de kinderen waren belangrijker. Verbeelding is betoverend, voor volwassenen confronterend.

Jurist die gespecialiseerd is in copyright en auteursrecht.

Je eigen proces uitstippelen. Je mag luisteren naar de afslagen die het project maakt. Je eigen reflectie op het project is belangrijk. Dat kan jij wel.

Ellen de Visser is Medisch Journalist bij De Volkskrant.

Gebruik de krant zoals zij jou gebruiken: tot wanneer kan je hier leren en wanneer ben je uitgeleerd? Het kan je (mis)vormen. Blijf gevormd naar je eigen mold, reflecteer.

Transformatie en reflectie, jij bepaald wanneer wel en wanneer niet. Dat maakt je een autonoom kunstenaar: luisteren naar jezelf.

De grote vraag wie ben ik? Hadden ze gemeen? Ben ik mijn ziekte? Dochter van? Welke rollen? Welke vragen?

Als je een diepte hebt ervaren die anders is dan het gemiddelde, dat maakt je tot een autonoom persoon.

