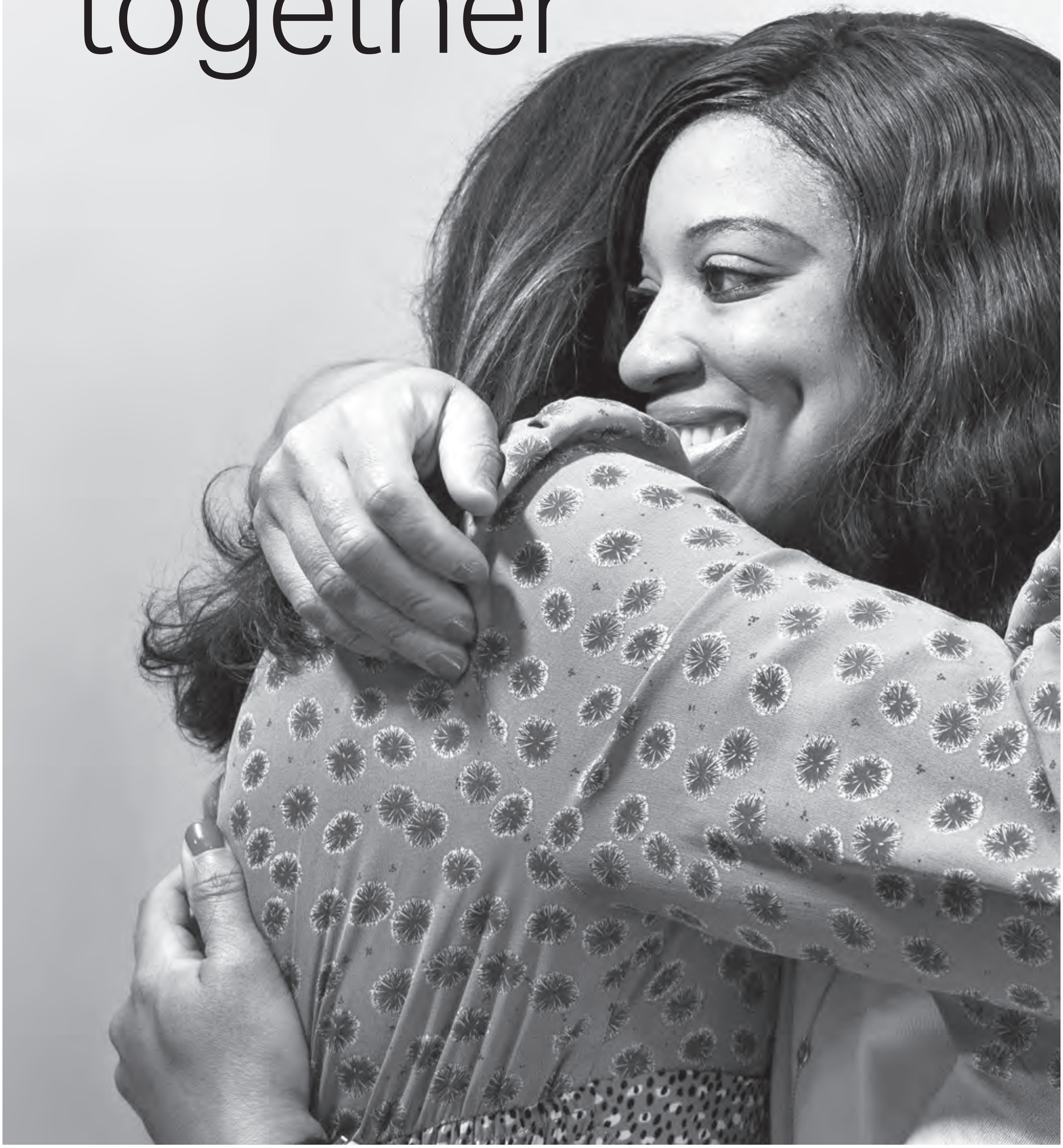
Portraying Parkinson's care

Holding still, together



RADBOUD UNIVERSITY PRESS

Thieme Stap, Richard Grol & Jur Koksma

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Colophon

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Part of the artist’s job is to make the commonplace singular, to project a different interpretation onto the conventional.

— Sally Mann, ***Hold Still:*** *A Memoir with Photographs*

Table of contents

From the perspective of learning

Roland Laan

Preface

Radboud university medical center's mission – to have a significant impact on healthcare – is realized by health professionals who work on it each and every day. Our staff's professional development is based on a number of pillars. First and foremost among these, we believe it is important that professionals provide and facilitate person-centred care, and that the patient is involved as a partner. This book focuses on this vital pillar from a thoroughly human perspective, and without trying to avoid the complexity of the task it presents. Person-centred care is collaborative in nature.

We also ask our employees to contribute to innovations in healthcare and to work together, regardless of whether that work crosses the boundaries of their own profession or discipline. Finally, it is important for us at Radboud university medical center to make our work future-proof and to create a healthy and safe working and learning environment for everyone. Our professionals make a crucial contribution to the training of future professionals. Professionals learn throughout their lives, so they must be able to take control of their own learning and development, be agile and creative, be able to broaden their perspectives, and take on new roles.

The Radboudumc Health Academy (RHA) aims to stimulate health professionals, prospective and current, so they can develop into 'life-long learners'. In the RHA, the learning, training, and education expertise are bundled. Doing research into learning is an integral part of this. Linking this research to teaching and work practice, directly helps to improve them. RHA researcher Thieme Stap's PhD research is a great example of how the RHA is working with departments in the hospital and with partners beyond to improve learning and work.

In addition to the research outcomes and the significance for healthcare practice, this project is already affecting education: the photographs in this book are part of a traveling exhibition visited by students and professionals who are interested in one primary question: what is person-centred care? This question quickly precipitates others, like how should I view the other person and how should I view myself?

We hope this book helps readers pause for a moment, and that readers ask and seek answers to these questions too.

Roland Laan
Director Radboudumc Health Academy

Introduction

Thieme Stap, Richard Grol, Jur Koksma

Person-centred care is a high priority for most healthcare providers. It is a kind of care that focuses on the person and not on the disease. Care tailored to the needs, wishes, and preferences of the person who is ill is increasingly being seen as a crucial aspect of high-quality care. Attention, trust, customised care, involving the patient as a partner, and the healthcare professional and the patient both deciding on the best approach are important aspects of it. There is now sufficient research available showing that person-centred care can contribute to better care outcomes and greater satisfaction: both for the care receiver and the care provider.

Person-centred care is especially important for people with Parkinson's disease. Parkinson's presents itself in many different ways: there is a huge amount of variety in terms of symptoms, limitations, wishes, and needs. It is also a chronic condition; people with it have to repeatedly rearrange their lives. This demands huge amounts of energy and strength, and the same is true of the courage they need in dealing with their disease. Nevertheless, it is important that the care is tailored to their wishes and goals as much as it can be.

Although the value of person-centred care is now undisputed, there is still a lot of uncertainty as to how it can best be put into daily practice. First of all, there are various interpretations of optimal person-centred care. Although the approach is becoming an increasingly important part of professional healthcare education, many professionals do not clearly understand exactly what it should entail for their patients. Workplace culture is not always beneficial either, nor is there always enough time for real interactions and conversations in the treatment room. In particular with Parkinson's disease, the focus is often more on the disease than on the person's specific limitations and the need for appropriate care.

Creativity is therefore hugely valuable for finding ways to provide optimal person-centred care. The project that this book is based on approaches person-centred care in a different way than usual in science; it uses insights from photography and narratives. Photographs provide an interesting addition to our understanding of person-centred care. Photographers have a specific way of observing and recording. The essay on photography examines this in more detail. Similarly, capturing personal stories of people with Parkinson's and care professionals provides unique insights into what 'caring' means. This is considered further in the essay on the value of stillness.

Research shows that participation in art (e.g. music, dance, and theatre) can lead to intensive learning, and it can affect professional skills (e.g. observation, analysis, and pattern recognition) (van Woezik, et. al., 2021; 2023). Specifically in Parkinson's care, a genuine tradition of working together with art now seems to have emerged (e.g. Shimura, et al., 2011, Wadeson, 2011, Garcia-Cascares, et al., 2018, Bloem, et al., 2018; Pelowski, et al., 2020). This is also true of photography in Parkinson's research and care (e.g. Crossley, 2015; Hermanns, et al., 2015; Leines, 2021). The project behind this book is grounded in this tradition.

The project

The project this book centres on is in line with these insights, and it uses artistic approaches to explore person-centred care. It looks at people with Parkinson's disease and their care professionals. How did we go about this?

We organised twenty-one sessions where people with Parkinson's came in for discussions with their care providers (e.g. neurologists, Parkinson's nurses, and specialised physiotherapists). They spent about an hour reflecting on what good care meant to them. These sessions took place in an unusual environment: a photographer's studio. Here, they were photographed, both together and individually. They talked about how they thought about person-centred care, their experiences with it, and what they expected from each other in the future. They also got to know each other in new ways through the personal objects they had brought along.

The audio of the interviews was recorded and transcribed. Together with the researchers, the photographer selected 12-15 photos of each pair. The researcher then presented these to the person with Parkinson's and the caregiver separately. They were to react to the photos, and the conversation about person-centred care continued. These conversations were recorded and transcribed too. Finally, the photos, stories, and quotes were combined. You will find the results in this book.

The book

In this book, you will find pictures and stories of twenty-one people with Parkinson's and twenty-two caregivers. The photos and quotes from the interviews are interspersed with a number of reflections on the themes of this book. The concept of person-centred care is discussed in depth: what is it, what is its importance and what should it ideally look like? The value of photography in research and care is represented, followed by two short essays on the power of imagery and stories in education. Then, a reflection on the importance of art in care is presented. Finally, you can read an academic essay about what the future of person-centred care for people with Parkinson's disease should entail.

Who is this book for?

First and foremost, this book is aimed at the large group of people dealing with Parkinson's disease, their partners, family members, and friends. We hope that this book will provide them with new perspectives on Parkinson's care and help them to discuss it with others. The book is also intended for the thousands of care providers who work hard every day to provide good care for people with Parkinson's disease. We hope it will give them a face and a voice. Finally, the book can be used in training medical professionals. The results of the project challenge them to pause and reflect on their visions of person-centred care from new perspectives.

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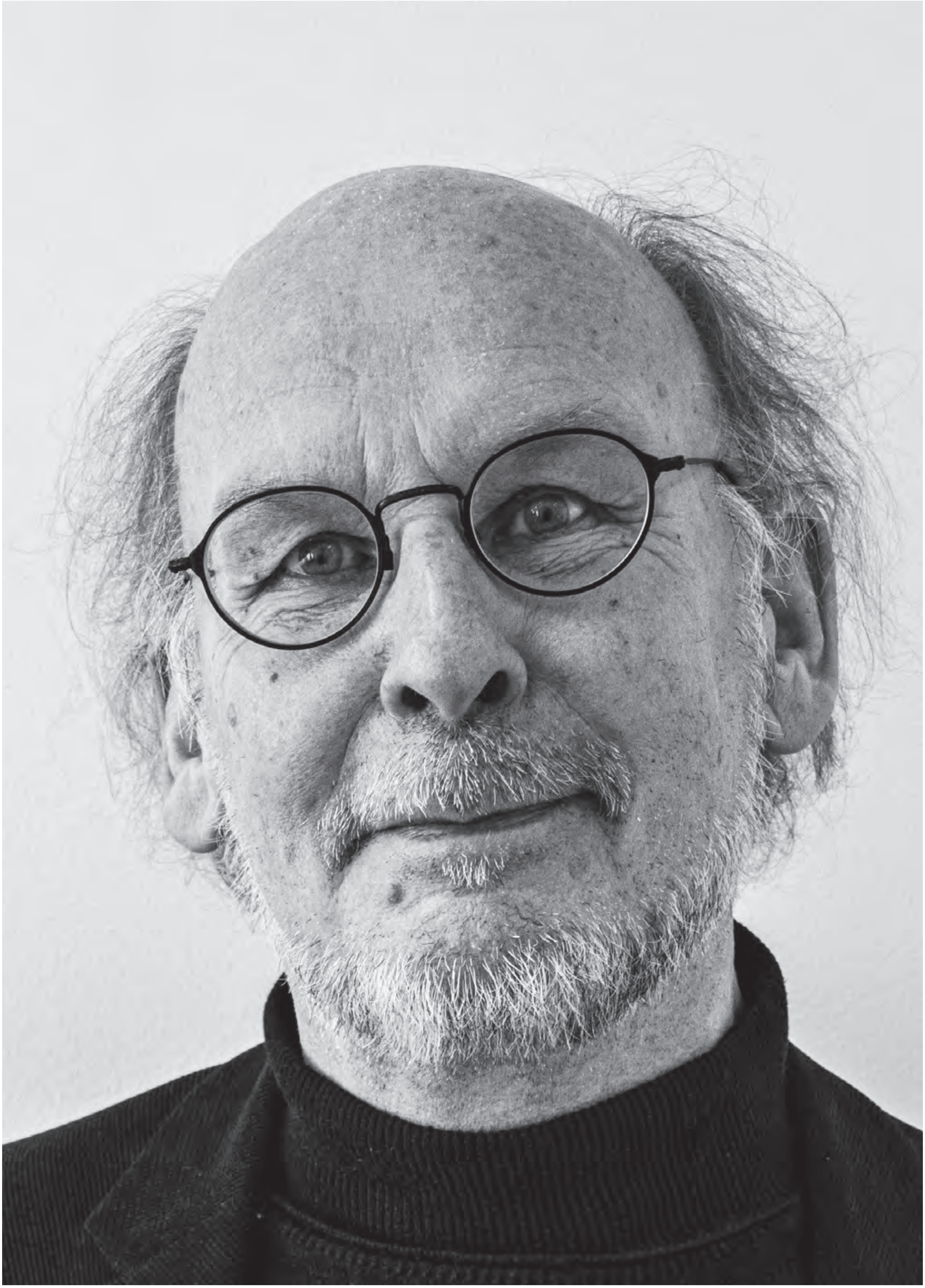
This is what the portrait says.
But there is in that gaze a combination
Of tenderness, amusement and regret, so powerful
In its restraint that one cannot look for long.
The secret is too plain. The pity of it smarts,
Makes hot tears spurt: the soul that is not a soul,
Has no secret, is small, and it fits
Its hollow perfectly: its room, our moment of attention.

— ***John Ashbery****, fragment from Self-portrait in a convex mirror, 1975.*



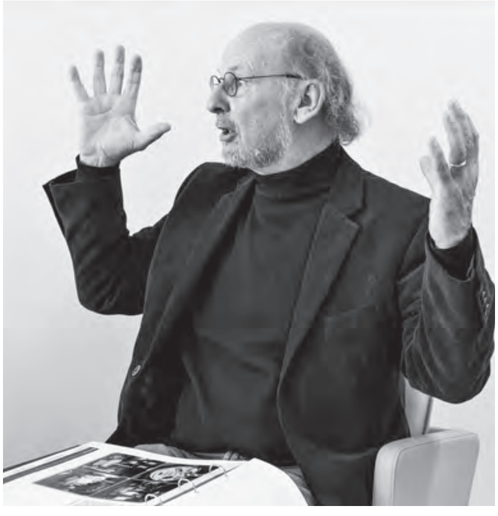
Bob

& Bas

Bob is creative

He works as a curator in different museums. He has had Parkinson's for more than ten years.

Bas has been his neurologist from the very beginning. Bas is a renowned figure within the world of Parkinson's care because of the many innovations he has brought about. Bob's wife commented that the two men find each other in their inexhaustible sense of enthusiasm and optimism.



Bas: I really enjoyed seeing 'Bob the curator.' I think that's what I always look for in the consulting room: the person behind the patient. There is so much we cannot see if we only focus on doing diagnostic tests, rather than taking time to get to know the patients. I think I can take better care of patients if I know they are playing the table tennis tournament final tonight.

Bob: Ultimately, Parkinson's has helped me. Of course, I have a creative profession and have been working as a curator in museums for a long time. When I was diagnosed with Parkinson's, I also took up painting. I'm incredibly active and feel like I'm becoming even more so.

Bob: When I think of my former General Practitioner, well, talking to him was like talking to a brick wall. An incredibly good doctor, but he was like a closed book. Our current GP is the complete opposite. He is very open and explains everything. I think you develop a bond with a GP when you get to know them better.

Bas: Showing the human side of being a doctor is not part of the curriculum. It's not forbidden, but it's certainly not taught in class. Showing patients who you are and listening to patients telling you who they are: this isn't a skill you're taught as part of the curriculum.

Bas: I know Bob is proud of his career. I don't see a guy with Parkinson's. This is a curator, and there's just an incredibly kind, pleasant person behind his Parkinson's.

Bas: If someone knows that Professor Bloem is also a volleyball player, then this improves the conversation. I discover more about him, and I let him discover more about myself in turn. I want to show that I am more than Bas Bloem the doctor, I am also the guy who likes to go on long walks with his wife in the weekend.

Bas: Both index fingers move, which is cool. You see the clinical perspective here. The interesting thing is – and you see this in people with Parkinson's fairly often – the mouth hangs open. His hypokinesia increases because he is working hard.

Bob: In this picture, I see the school teacher and the pupil. I don't know if that's bad, because it's just an exercise, but it may also be difficult to get out of that particular mode.

Bas: One gets to this so-called 'medical mode' very easily. But it is precisely by talking about his work that you can actually comprehend how he deals with his illness. You see, if you think about it, the funny thing is: wouldn't facilitating consultations like these improve the intimacy between the doctor and his patient?

Frans

& Lisa

Frans
was an inventor

A real ‘Willie Wortel’ (Gyro Gearloose, from the Donald Duck comics), as his wife lovingly called him. For years, Frans worked for Philips in an innovation-oriented department.

Lisa is a neurologist who loves the sea and tries to focus on the person behind the Parkinson's. Frans had Parkinson's since 2009 and sadly passed away in 2019.

Frans: This is something I made from some pieces of wood I had lying around. So you know, at Philips I was always busy developing and creating things. It is second nature to me, this inclination towards invention and creating better tools. For every kind of pill, you would have something like this: a 'pill pusher.'

Lisa: What I like about what you told me about your work is that you always tried to bring out the best in people. We at ParkinsonNet strive to do this as well. And this isn't only true for ParkinsonNet, the nurses on the ward and the entire team of physiotherapists want to achieve the same goal.

Frans' Partner: The professor sat down in front of him and said, 'I have two announcements, a good one and a bad one. The good news is: it won't kill you. The bad: you have Parkinson's, and you will have it until the day you die.'

Lisa: I knew Frans really wanted to keep playing golf. So then we started focusing on how we could achieve this goal: could we achieve it with medication? With physiotherapy? One person wants to play golf, another wants to do something else.

Frans: Conversations are better if the patient is able to – and does – prepare. I was used to doing that for meetings. I'd write down the points I wanted to discuss on a piece of paper beforehand.

Lisa: I only see the person, so to speak; I don't see Parkinson's. If I have known someone for a long time, I also have to remind myself to keep in mind the seriousness of their Parkinson's.

Frans' Partner: That's what's so great about the new hospital. The health professionals are able to contact each other directly. If there is an issue, it is immediately passed on to a colleague or you are referred straight away. Communication is very efficient.

Frans' Partner: My husband has fallen a lot in recent years. While playing golf, off his bicycle, even off a tricycle, just last week. So far, we have been lucky that he has not broken anything. We think his volleyball training may have had something to do with it.

Frans: Volleyball training has taught me that falling safely is about bringing your centre of gravity to the ground as quickly as possible. It's a matter of practice. Try not to fall to the ground like a brick or a sack of potatoes, but roll. Maybe it helps, I don't know.

Lisa: I think you create an image of someone over the years, just from the little things. In this image, you see the person, you don't see Parkinson's.

Chris

& Marlies

Chris was a psychiatrist for many years

She was diagnosed with Parkinson's disease twelve years ago, but likely had it for longer. Music is her life.

Her physiotherapist, Marlies, uses this passion in her treatment.

Marlies: I think the more you are yourself, the more people will trust you. Some people don't want to share a very personal bond. With other people, you become more personal. It also has to do with my own preferences, undoubtedly. I share more of myself with some patients than I do with others.

Chris: I brought a tuning fork. I'm in a choir and I like to sing. A conductor can get all the voices in harmony by using it. I want to use this tuning fork as a symbol to show the meaning of music in my life. Music is very important to me. How it is able to communicate your emotions, your sadness, your joy, your energy. Singing together, making music together. I've done that from an early age. It is such a wonderful gift.

Chris: Last year, when the neurologist told me it was Parkinson's disease, it felt like a death sentence. I don't feel like that anymore. Now, when people hand me a coat, for instance, I think, 'Let me do it myself!'

Chris: The method Marlies taught me is about moving to music. It is about integrating motor skills. Your whole brain gets involved. And yes, it makes me happy too.

Marlies: It's a multi-sensory exercise method. You use rhythm, colour, and sound. You move. And you do all of these things at a set time. It's like sheet music, where you do something with your hand on a beat, and you do something with your foot on the next. When a person's focus is not on the movement itself during an exercise, you can make it into a double task and train to do two things at once.

Chris: Marlies is very attentive. I trust her a lot. But for me, it also feels like there is an imbalance because I don't give anything back. I receive a lot. I always go home comforted, even when it's difficult. If it isn't difficult, I go home happy. The only thing I give back to her is my trust. Sometimes, it is like I'm worth less if she gives more to me than I give to her.

Chris: In the beginning, I was very anxious and insecure. Then, Marlies put on music for an exercise. I have a knack for learning music, so it was great to do. If I moved too fast, she would say so and touch my fingertips, and that sensation went through my whole body. Then she said to me: 'You're so musical!' I told her about my passion for music. Then she said, 'You know, you telling me about this gives me goosebumps.'

Chris: Right now, I'm the patient who is having trouble accepting that she has Parkinson's. This week, I was at the doctor's office for an inflamed foot, and one of the staff said: 'Oh, that's Parkinson's.' It upsets me. I'm not Parkinson's, I'm not a stomach, I'm not a toe, I'm a person. I always fought for that when I worked as a psychiatrist, and now it's happening to me.

Gert

& Ramona

Gert's job was to maintain pipe organs in churches and concert halls

He travelled a lot for his job. Since he got Parkinson's disease, some ten years ago, he has had to stop.

Ramona is a district nurse who has gotten to know Gert over the last few years. She specialises in Parkinson's disease.

Gert: Ramona is a very nice woman who is always positive and has ambitions beyond her 'Buurtzorg' work. If I have questions about Parkinson's, she answers them immediately.

Ramona: I think Parkinson's disease is very complex. It has many consequences. That has always fascinated me. I do think I am a very motivated care professional, someone who is fully committed. I am very enthusiastic about my work. I like to take things on, and I'm not one to say 'no' easily.

Ramona: Gert always has a story ready. He has something new to tell me every day.

Gert: I am a pretty self-reliant person. I always want to try to do things myself and Ramona is great at allowing me to do so. There are nurses who are used to constantly helping and sometimes I have to ask them to give me some space because I want to give it a try myself first.

Ramona: I know colleagues who like to give hugs. For me, touching is more functional.

Gert: What strikes me in the photos is that I have such a prototypical Parkinson's posture. It's quite confronting because you don't really notice it yourself. Head and shoulders forward, arms hanging down. There's nothing you can do about it. But now I suddenly see myself as a patient again.

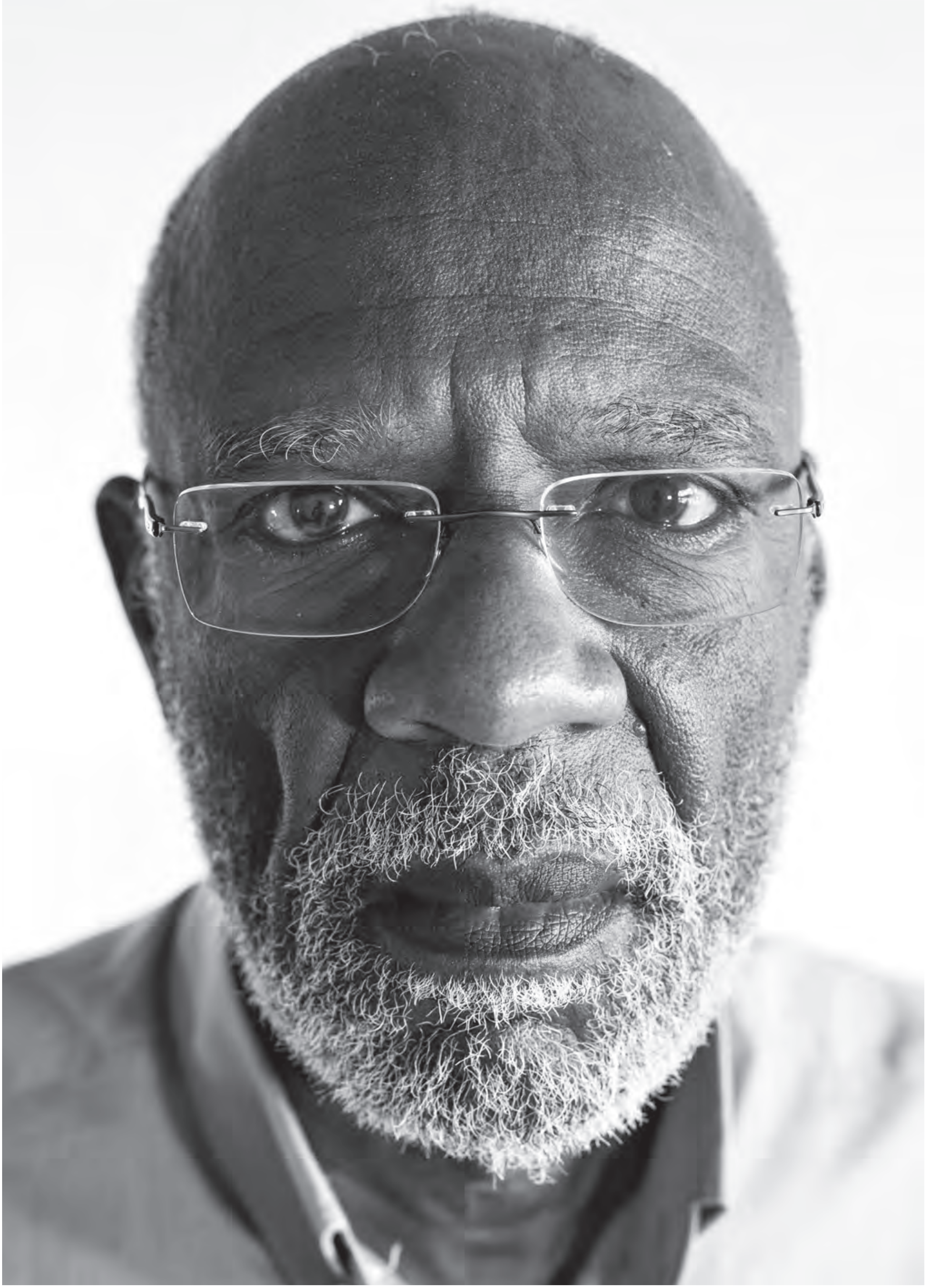
Ramona: I have noticed that there are some of my colleagues who want to solve everything right away. You have to be careful with that. You cannot offer solutions if you don't know where the problem is. Sometimes, you have to wait and see how it develops; not act too rashly.

Gert: What I lost because of Parkinson's is that I can't play the organ anymore. It's a great loss because I always enjoyed it very much.

Gert: During my time in America, I spent a lot of time in a hotel room. There, I saw a medical programme on TV where they said that Parkinson's often starts with losing your sense of smell. In my case, that was an indication that I did have Parkinson's because I had completely lost my sense of smell.

Ramona: Quality of care improves a lot if you have a good relationship with your patient. If you know someone well and have a good relationship with them, it is an investment for the future, if their health starts to deteriorate, for example.

Gert: One of the personalised aspects is that you get a team of caregivers that always includes the same people. That is important to me because you can build up a relationship between the caregivers and the client. It is very valuable because you don't have to repeatedly tell people your story.



Edsel

& Rinske

Edsel worked as a psychiatrist for many years

Edsel has had Parkinson's since 2008.
He rehabilitates in the clinic with his doctor, Rinske,
who has a central role in the process.

Rinkse wanted to become a tropical doctor but
chose to become a rehabilitation doctor based
on personal experience.

Rinske: At first, I wanted to become a tropical doctor. But I changed my mind. I was twenty-five, twenty-six at the time. I went to Nigeria with the idea that I could do something good. Maybe a little naive, but it wasn't quite what I imagined. How the people live, but especially how care was regulated, or in this case, not regulated. It was quite a culture shock when I returned. I was like, 'How well-organised are we in the Netherlands?!' I've seen people die who didn't need to. If I had to work in a world like that, I'd be completely burnt out after just a couple of years. But I did also see beautiful things, like a woman who came in and had her fourteenth baby.

Edsel: In my work, if there were any problems, they asked me to sort them out. I was fairly authoritarian. If agreements were made beforehand, we had to stick to them. Otherwise, it would end in a fight, and nobody wants that.

Rinske: Pain is a theme, I would say. It's a known problem for people with Parkinson's. But it's a search. We work on managing it with you alongside different therapists, but it's difficult.

Edsel: All of my family lives in Curaçao. Everyone except me. It used to be very different. If you made a phone call, it cost almost five guilders a time, so you didn't call all that often.

Edsel: My time is running out, now. It's kind of determined. It's a bit of an ordeal. I used to be scared of getting dementia when I retired, but now I feel like death is getting a little too close for comfort.

Rinske: Being a rehabilitation doctor is sometimes seen as a luxury specialism. I think it's just as important as trauma care or pills from the neurologist. Maybe even more important because it's about having a life worth living.

Edsel: The important thing for me is that I will be in less pain. Back pain, pain in my arms, pain in my legs. I'm defenceless and pain is a predominating thought. It's also hard to deal with the fact that I keep getting worse cognitively. When I look into shop windows, I can already kind of see the 'Parkinson's walk' starting to form. I'm moving in that direction.

Edsel: Care is well-organised in the Netherlands. It just takes a long time. When I was a doctor myself, I sometimes thought it wasn't that difficult for patients to ask me questions. Now I'm a patient myself, I know it's not easy. Rinske: I came back from Nigeria without a plan. So I thought, 'What else did I like to do during my residency?' I discovered rehabilitation because I was a patient after a car accident. I know what it's like to lose independence. It taught me a lot. For example, a doctor brought their residents along during a round. They started talking about me while I was there. I thought, 'Hello! Explain? What do you mean?!' Those were the things that made me determined to do things differently.

Edsel: Parkinson's is always with me, or next to me. It's like I have a friend, you know? But he's unruly. I can't send him away. Most of the time I feel like we're good friends, but sometimes I think 'Go away'. He always makes me evaluate things. I am in a lot of pain. I always lock him up in the back of my mind, but sometimes he still manages to get out.

Rinske: I didn't know how your children were dealing with this process. Your wife is usually with you. I get the impression that she has a very good understanding of what is changing and that she is able to adapt.


basalt

The heart of patient-centred care

Jan Kremer, Glyn Elwyn

On a cold spring evening in 2001, in my role as Chair of the Department, I arranged a meeting with ten couples dealing with infertility. I wanted to know about their experiences with our IVF department. I began the meeting thinking that we were doing a pretty good job. However, the patients did not agree: 'Our needs and expectations are not central, we feel like numbers, we see high and low-quality care, and we have noticed that some doctors lack social skills.'

It was tough feedback that touched me deeply. I was even more impressed by the latent power in the group, a power that we did not use sufficiently. We considered patients to be passive, and I realised that we needed to harness their power so they could become active partners in clinical processes.

We started to innovate in our IVF department, with the aim of organising our care around patients' needs. We developed a digital IVF clinic and gave our patients access to all their data. We built a digital community where clinicians and other patients could answer patients' questions. We uploaded our information leaflets to an online wiki and asked patients to update and improve them. We asked patients to help us write and implement guidelines. We tried to view the quality of care through their eyes and introduced shared decision-making. For example, we started involving them in deciding how many embryos to implant in the uterus.

It was a significant change for the better in the department. It was also clear that my career as a clinician had to change if I was to take these ideas to a wider group of people.

– Jan Kremer

What is patient-centredness?

In 2001, the Institute of Medicine (IOM) in the US identified patient-centredness as one of the core elements of quality of care (Relman, 2001). The IOM had already recognised five domains of quality of care: effectiveness, efficiency, safety, accessibility, and timeliness. Patient-centredness became their sixth domain. According to the IOM, patient-centred care is care that "respects the individual preferences, needs, and values of patients. and that guarantees that these values guide clinical decisions."

This definition was important, yet putting it into practice was and is still not straightforward. The Picker Institute, an international organisation that wants to include the patient's perspective in healthcare, distinguishes eight dimensions of patient-centredness (Gerteis et al., 1993):

- Respect for patient's values, preferences, and expressed needs
- Coordination and integration of care
- Information and education
- Physical comfort
- Emotional support and alleviation of fear and anxiety
- Involvement of family and friends
- Continuity and safe transition from one care setting to another
- Equitable Access to care

These dimensions give more meaning to the concept of patient-centredness. It is not the same as 'patient satisfaction', a subjective concept determined by a patient's evaluation of their experiences in specific contexts. Patient-centredness is about more than just being nice to patients: it goes much deeper.

The ethical foundations for patient-centredness

Why is focusing on patient-centredness the right thing to do? Why are so many people enthusiastic about this aspect of quality of care? According to Anne Duggan, Professor at Johns Hopkins University, the moral nature of patient-centredness can be viewed from three ethical stances: it can be viewed as a duty, as a goal, or as a virtue (Duggan et al., 2006). The ethics of duty views patient orientation as a calling. This was probably more common in the past than it is these days. Consequentialist ethics puts the emphasis on outcomes of actions. Does an intervention improve medical outcomes, or does it reduce costs, and may it act to prioritise the intervention rather than the person's views and priorities? Virtue ethics embraces the idea of doing what is morally good or helpful to the individual and ensuring that you know enough about the person to act in their interests. Patient-centredness is about balancing these three ethical stances to interact with people, to learn from the process and how they give meaning to clinical work, a sense of purpose, and create a more meaningful relationship with the patient.

Is there a need for healthcare to become more patient-centred?

The idea of putting patients' needs, priorities, and wishes at the centre of all decisions is not novel. The term patient-centredness was coined in the 1970s (Henbest et al., 1990), but the idea has always been fundamental to medicine. However, there is evidence that in today's world, healthcare struggles to balance the need to put the right emphasis on human values while being sufficiently respectful to the person, their context, and their needs. Many factors make this difficult. Healthcare is more fragmented, and it is often delivered by large teams who struggle to fully communicate with each other. More often than not, patients experience disjointed episodes of care from multiple different people. Technological and pharmaceutical advances lead to complicated plans that involve complex investigations, operations, and a number of new medications. A generalist in primary care or a family doctor might be expected to be the link to all these different processes, but they are often not well-informed about this fact. The need for compassion, kindness, and curiosity about the best course of action for individual patients becomes even more important as healthcare's ability to address illness increases and as health delivery systems get more complex.

What does research say?

Research tells us that people want to be respected as individuals. They want to be informed and heard and feel that their views are being taken seriously. Even people who say that they always want clinical professionals to make recommendations and make decisions expect personalized care, tailored to their contexts. Unfortunately, decades of research also tell us that clinicians do not always exhibit the skills required to meet these expectations. Many clinicians are unable or unwilling to explain complex terminology in language that people can grasp. Some clinicians lack curiosity about the person in front of them and fail to gather information about their family, their interests, their challenges, and what brings them joy. A large number of studies also show that clinicians are not able to share decisions with people, even when there are clearly important options that could be considered (Elwyn, 2020).

Relevance to people who have Parkinson's disease

Living with a diagnosis of Parkinson's disease is a constant challenge, as a person who was once well struggling with a changing identity. The tremors and the stiffness become slowly visible to others, but the wider impact is much less understood (Brod, Mendelsohn, and Roberts, 1998). Speech becomes more difficult, slower, and quieter. Getting ready takes longer, as does eating and getting dressed, so frustration grows, and anger manifests (Backer 2000). Living means taking medication by the hour and navigating the fear of being 'on' or 'off', or having no control over sudden jerking movements that can be intensely embarrassing, and regaining some semblance of control requires tremendous effort. People who have Parkinson's disease have a clear memory of who they were. As Charmaz noted, they face a daily struggle between the person they have become and the person who could previously move and think clearly and they, like many others with long-term illness, "resoundingly reject identities founded in invalidism. They do not wish to be a patient first and a person second" (Charmaz, 1987). Being truly patient-centred, paradoxically, means not viewing the individual as a patient with an illness at all. It means getting to see and know the person and not the disease.

This book is an impressive attempt to see the person behind the disease. The combination of images and citations seduces the reader to focus on what the disease means for the patient as a person.

Next steps

The IVF patients I mentioned at the beginning of this chapter were right. They were not numbers or objects: they were people with unique stories, which means they should receive tailored solutions that fitted their priorities and context. The purpose of patient-centred care is to improve people's quality of life.

It is not about what doctors do, it is about the solutions that they and their patients can co-design to solve problems. Reflection, embracing personal narratives that use stories, memories, music, and images, as presented in this book, are some of the tools we can use to develop true person-centred care.

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Omotola

& Ray

Omotola has had Parkinson's for ten years, since she was 29

During our session, she met her Parkinson's specialised nurse, Miriam, whom she hadn't seen for more than a year.

Her neurologist, Ray, was present at this meeting too. Ray and Omotola advocate the importance of ethnicity in understanding Parkinson's.

Omotola: I brought the microphone because it represents an opportunity for me to communicate my thoughts, communicate my desires, communicate with my healthcare practitioner. Practically for me, as an African person impacted by Parkinson's disease, this microphone represents an opportunity to lend my voice to my people. Africans are largely underrepresented in research, trials, and conferences. It's very, very personal to me.

Ray: I come from a very medical family. My father was a doctor so I didn't have a choice. I am actually a fourth-generation medical professional; my great-grandfather and grandfather were doctors too. I only have one brother who escaped!

Omotola: I have been tested at this hospital for genetic mutations of Parkinson's. It came back negative. Now my question is: was it negative because I didn't have those mutations, or did it come back negative because we don't understand the molecular background of Africans who have Parkinson's?

Ray: It is important to have role models. They won't listen to me. I make a video, sure… but if Omotola made a video, the chief executives would listen straight away.

Omotola: I think people are starting to listen. Africans are getting more involved and empowered in the conversation. I hope to change the Parkinson's care landscape in Africa.

Ray: Many institutions are still inherently racist. The problem is, if you want to raise issues like race, they ask you where the evidence is. So, we provide the evidence. However, it has taken me a lot of time to find funding for projects like this.

Omotola: I know this sounds weird, but for a long time, I thought I was the only African with Parkinson's because I had never met anyone else. I felt very alone. Not because I didn't have support but because I had great support here at King's, I have great support at home and a lot of support from my British and American friends. However, I didn't meet any Africans.

Ray: The research we have already published shows atypical patterns in the African population. It is based on the diaspora we have here. These are first and second-generation African people. In addition to those living in Africa, it includes Caribbeans with African ancestry.

Omotola: When I lost my motor skills, I lost the ability to do my and my daughter's hair. It was a painful experience. Ray: What we and Omotola are trying to focus on is Parkinson's in the non-white, particularly the black, population. We still need to do a lot to raise awareness.

Omotola: I think I am spoiled here. I have access to such wonderful people. It is so important for my wellbeing. If there is something I need, I can send an email, a text or a WhatsApp message, and I don't have to wait for three weeks for a response. The most important thing for me is access. They are there when I need them.

Omotola: They do a lot of research on ethnic minorities here. I wanted to be part of the community. I wanted to be part of the team. To be sure that I am not being generalised.

Omotola: Faith puts me in a position where I am able to hope and believe. Parkinson's affects your mental state. Fate gives me hope and keeps me positive.

Ray: That is really important. Care needs to be personalised. We do not use a one-size-fits-all approach, which, unfortunately, cannot be said for some of my colleagues.

Resi

& Lidwien

Resi is an anthropologist and used to work as an art teacher

She has had Parkinson's since 2011.
Resi and Lidwien share a personal connection.

Lidwien's work as an occupational therapist
has made their relationship remarkably profound:
she helps Resi to live with Parkinson's day-to-day.

Resi: The concept of illness has to do with disease prototypes. I don't see Parkinson's as a disease, actually. I still consider myself to be incredibly healthy; I only suffer from mobility problems and stiffness. For the neurologist, it's his profession, he needs a certain objectivity, things he can diagnose. But his diagnosis is not necessarily about me as a person.

Lidwien: By showing a certain vulnerability or openness, you give others the opportunity to tell you something; if they don't do so already.

Lidwien: I consider 'embracing' a much warmer, more accurate description of the process. You either embrace the fact that things in your life are changing, or that you are limited in some capacity. You embrace Parkinson's.

Resi: I would like to see what my path is, roughly. I think life is worth living. It's going to be quite a challenge to let go of that. But if I have to, I want to do so in a positive way. I hope to acquire an attitude that means I am ready for it.

Resi: I'm a little slower now, but I do try my best to understand as much as I can about what drives people to be human.

Lidwien: I can't do it alone. A physiotherapist can't do it alone. The psychologist can't do it alone either. You need a whole bunch of people, especially with Parkinson's.

Lidwien: Of course, you have a treatment plan with Parkinson's, so there are some set things that you inevitably end up looking into. There's a structure you can't change; there's a disease you can't change. But the real challenge is exploring the boundaries with each other and starting to look for what it is that someone needs to progress based on what is essential to them.

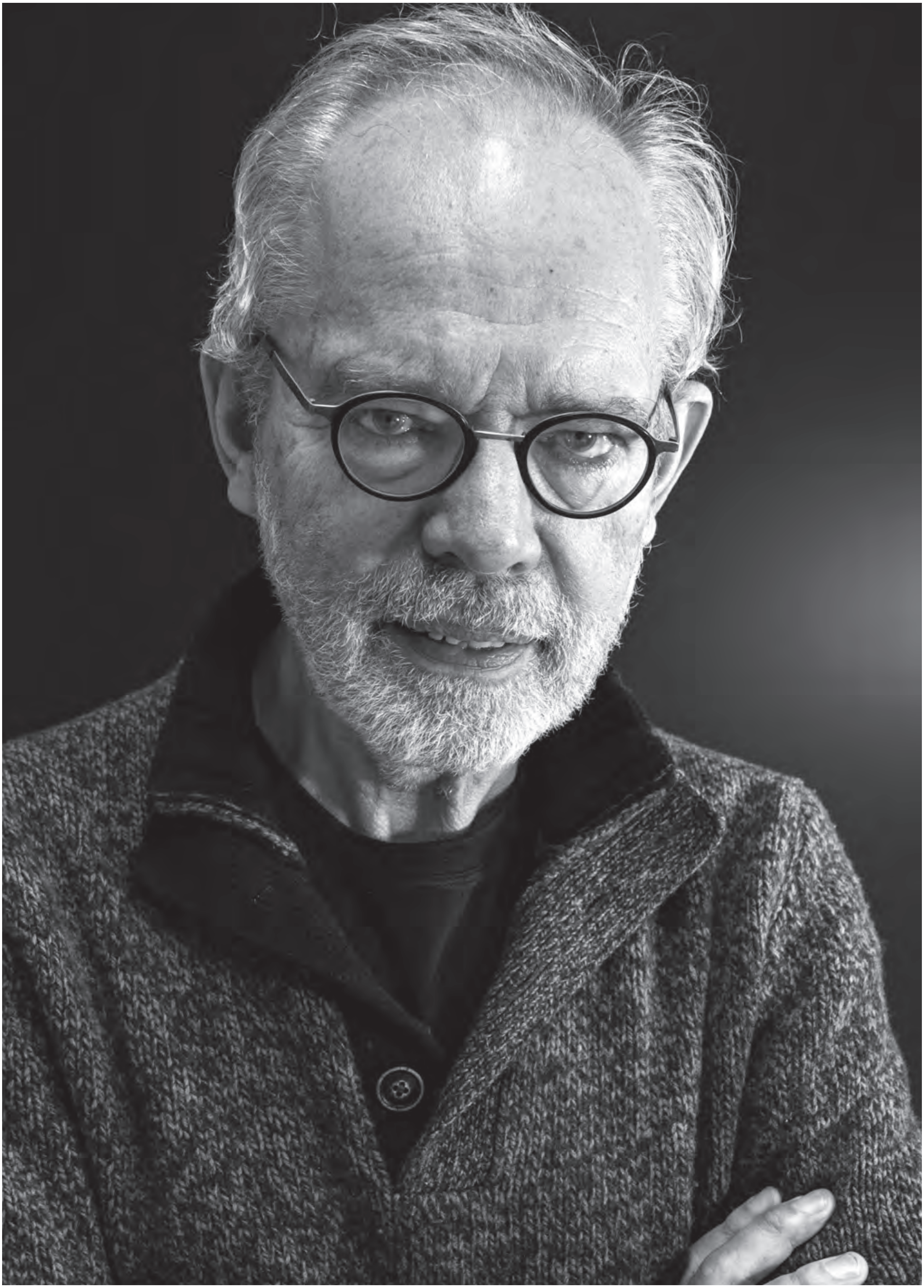
Resi: It's like our conversations about how I can think of little tricks that help make that sandwich in the morning. And about how to remain calm if you're very slow – that sounds weird – and how to respond to the certain mental abnormalities that Parkinson's brings. Putting things in perspective, learning to keep yourself under control, and so on. The fatigue, of course, the lack of energy. That's exactly what I'm talking about.

Lidwien: You grow in your profession. When you are new to occupational therapy, you don't get to experience many complex situations, because you don't know if you can deal with them. In recent years, I have seen situations in which people are seriously ill or about to die. It makes you realise the value of your profession more. That's my driving force.

Resi: That neurologist often says, 'You have to do this. You have to do that.' They teach you basic exercises, but they aren't of use to me. I never move like that. Why should I care if I can make these movements? I care about a pan of eggs falling out of my hands. I care if I trip over something. Do you know what I mean?

Lidwien: Everyone has their own way, their own emotions, and their own opportunities. Can you create the openness for people to find out who they are? What can they do as human beings? Where do they get their strength from?

Lidwien: I visit people at home. People don't come to my practice much. I literally come into people's lives as a guest. I watch how people lie in bed, go to the toilet. You're involved with very personal things. They open the front door to you. I often get excuses from people: 'Don't mind the mess.' I always think: 'I don't care about the mess, I've come here just for you.'



Willem

& Jacqueline

Willem is the son of a miller

Willem used to be the spokesperson for the local university. He has had Parkinson's for a few years, and sees Jacqueline, a Parkinson's-specialised nurse, every six months.

They share a background; they are both from a rural area where they learned to work hard, but they also share basic trust in their relationship.

Jacqueline: Willem has a friendly disposition. It doesn't have anything to do with his vulnerability because yes, he is vulnerable. He is affected by his illness, but he is still able to do many things easily. Your sympathy for him just has to do with the fact that he's a nice, friendly guy.

Willem: I am a miller's son; there were four generations of millers in my family. I was wonderfully happy at the mill for the first twelve years of my life. Things were so peaceful that I am convinced that my parents provided me with the lifelong ability to be able to take things as they come. The most essential thing I have learned is to trust.

Jacqueline: I liked the stories about Willem's house at the mill. For me, from an ethical point of view, I sometimes hesitate about whether I should continue to pry. Sometimes, I think it's nice to know a little bit more, especially if it's about problems that someone is experiencing. I am not a psychologist, but I am interested and involved. This photograph helped me to travel back to Willem's past; I had never gone back that far with him.

Willem: What I consider of crucial importance is that I really don't want to be viewed as a patient. I want to go on living an ordinary life for as long as possible. When I visit others suffering from Parkinson's, I can feel myself being put in the patient category. In the consulting room, I am a patient. Of course, I am a patient, I know that, but I just want to maintain a rational position towards it.

Jacqueline: I come from a farming family where people had to work hard, and I inherited a kind of work ethic. Keep going, put your back into it. In patient counselling, I often think about how terrible it is that this is happening in the patient's life. But then I support them because we do have to get on with it. I always hope that my patients do not just linger on.

Willem: Jacqueline is actually the stable factor in my life. Doctors often change. It's nice to have my own anchor point; someone who knows the history of my disease.

Willem: What I like is Jacqueline's empathy. The calmness to ask how someone is doing. Then I talk about my loss and say things like 'I'm a bit sad that I am no longer able to do this.' She gives me the space to express these feelings.

Jacqueline: I had a low point in my life: my first husband was seriously ill, and I didn't think he was going to make it. You have to move on after that, though and do so in the most positive way possible. If you remain angry or disappointed about things that have happened to you and you can't deal with them, it's a crying shame.

Willem's partner: I think it's very important to have a good relationship with a care provider. If that's not there, you don't have trust. And trust is pivotal, certainly during long-term processes. Parkinson's is a chronic disease that can go on for years. Then you just have to trust your healthcare provider.

Jacqueline: I think, professionally, I try to give people confidence. Like saying, 'You can do this!' I don't say it exactly like that, because I don't think that's the right approach. However, I do try to talk about what someone always liked to do and what they enjoyed. I think I use it indirectly.

Willem: I feel comfortable with people quickly: I trust them. It's a very important foundation for a good patient-carer relationship. That the patient also trusts the carer. Not a blind trust, but true trust.

Noud

& Chyntia

Noud worked as a psychologist

Noud has Parkinson's, but practicing Zen Buddhism helps him to deal with it. Noud and Chyntia see each other once every six months.

Chyntia is a nurse and works both in a city hospital and at an academic hospital.

Noud: Many care providers quickly figure out what I should want and what I need. Then I think 'Wait a minute, take a minute, listen a minute.' Many care providers tend to provide care irrespective of whether it is necessary. Attention is key; taking the time to listen to the patient. I get the impression that care providers are trained to listen to what is going on, according to the old diagnosis-prescription model. However, for the patient, it may be enough just to express what is bothering them.

Noud: I don't want to be patronised... I have had that attitude for a long time, even before Parkinson's. I want to have a say in what happens.

Chyntia: Empathy is about being able to empathise with certain things, not just with patients themselves, but also with their families, family caregivers, and their children.

Noud: Parkinson's to me is a kind of accelerated aging of the system. In this case, the system is your body, your feelings, your thoughts, all that gets a little slower. It takes longer to get dressed, so I get up earlier. These are small frustrations; incidental and transient.

Noud: I know that I am able to look cheerful. My face has become tight compared to what it was before. I used to look more friendly. That's one of the downsides of Parkinson's, that you're not judged by who you are as a person, but by how you look. A straight face can look stern or grumpy.

Chyntia: I think it's very important in my profession, that you can take the lead because there's a lot involved in care. There are a lot of caregivers involved and everyone wants to do their own thing. But the patient has to be central, and I feel like that tends to be forgotten. Then it is my job to call everyone together and to ask the patient 'What do you want?'

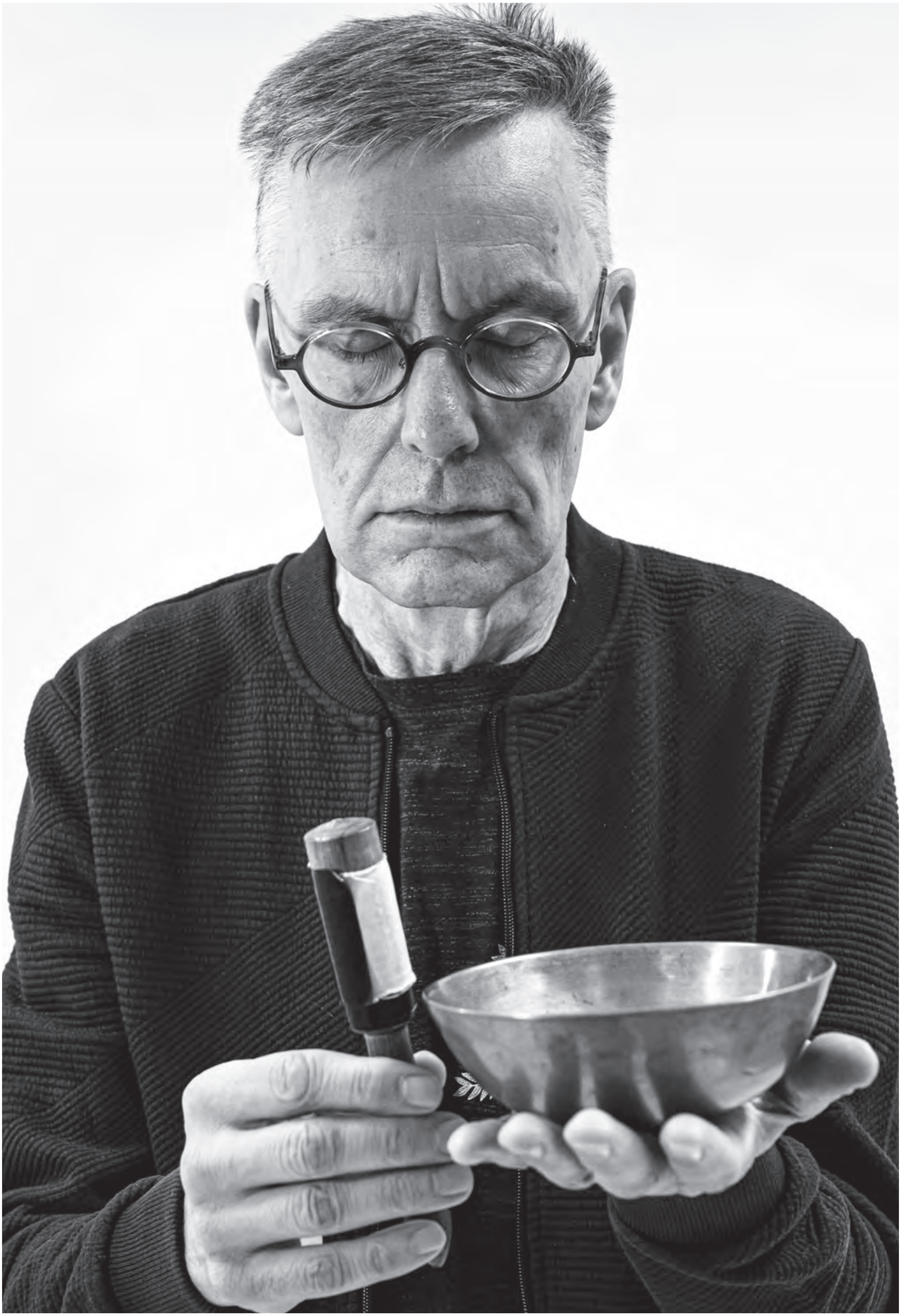
Noud: I feel strongly that I am not my body. I am not my Parkinson's. I would describe it as a representation of me, but not the real me.

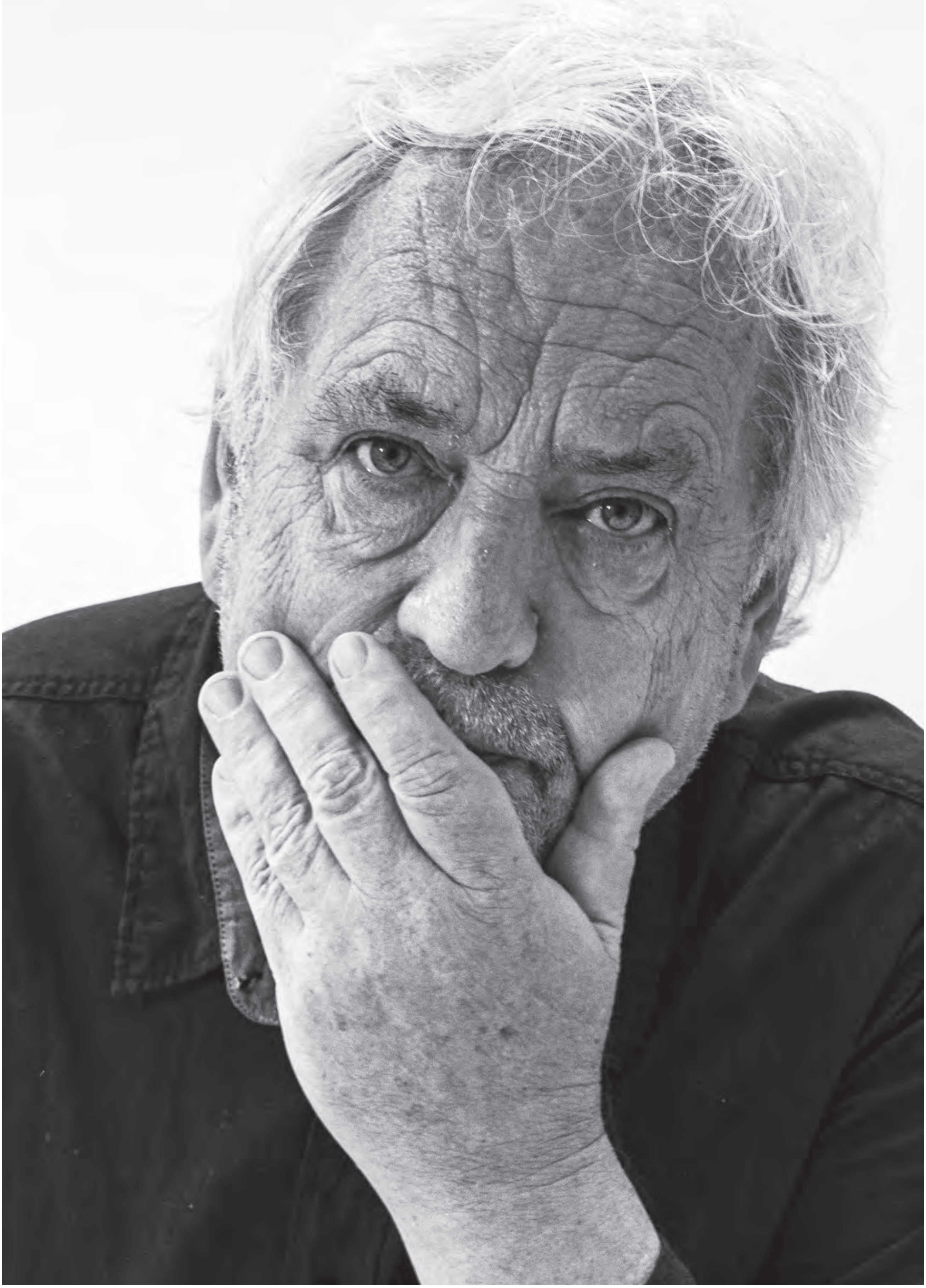
Chyntia: I think korfball has shaped me as a person. It has helped to give me the confidence to take the lead in processes. Sometimes, the patient needs to talk, I think that's very important. But sometimes, there are patients who cannot take the lead. If you, as a care provider, can't or don't dare stand up for what the patient wants, then you have a problem.

Chyntia: Informal caregivers sometimes have an even harder time than the patient. They quickly become overburdened by Parkinson's. They experience even more support from you as a Parkinson's nurse because they can tell you their story. They feel that you understand and can give them the tools they need.

Noud: Mindfulness has to do with having an open attitude, being as unprejudiced as possible, not judging too quickly. Staying with what is happening in the here and now, not what happened long ago or what is going to happen in the future. I am not in the habit of making demands as to what my life should be like. Things can happen, situations that you don't foresee or can't think of beforehand. My experience so far is that if I take the time to look at the situation calmly, then it is actually not all that bad.

Chyntia: There was a moment Noud put his hand on my shoulder. There are a lot of discussions about how close patients are allowed to get to you as a caregiver. Usually, I think it's fine, people don't cross boundaries with me. I liked the fact that Noud just did it: he didn't cross any boundaries. It felt like he was saying: we are a team, and we are working together to provide better care.





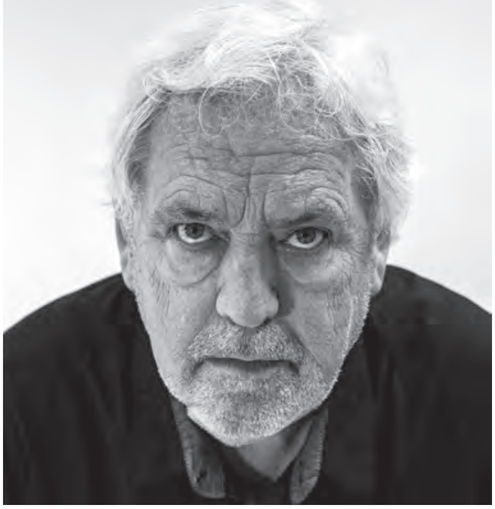
Ernst-Daniël

& Margit

Ernst-Daniël is one of the most famous opera singers in the Netherlands

Ernst-Daniël has had Parkinson's disease for a few years. He wrote a play about the things he couldn't do anymore.

Margit is his psychiatrist. During this photography session, they decided to put on a bit of a play. You can see the results here.



Ernst-Daniël: That's the horrible thing about Parkinson's: you lose your confidence. That's how I experience it. I used to be able to talk like no one else on television, but now I try to hide from the public as much as possible.

Margit: There are people who just want you to get the diagnostics right, and you don't have to be nice to do so. They say, 'I just want to know that you've answered everything and that the diagnosis is correct.' Others say, 'I don't really care about the name of my disease, as long as I receive help. Hey, as long as you help me and you're there for me. I would appreciate it if you are involved in the process.' What people want varies a lot.

Ernst-Daniël: My heart's not in it anymore. Yes, I used to be the Ernst-Daniël, that nice weirdo, but that's all kind of gone. He's babysitting a bit, playing grandpa.

Margit: I have a number of role models when it comes to physical contact. Namely, the psychiatrists who trained me, who believed touch was important. Not all psychiatrists do. There are also those who do not feel it's their place to touch patients; there is a distance between the patient and the practitioner that should be maintained. I'm not going to do that. But yes, I think it's a very nice gesture to let people know you're there for them.

Ernst-Daniël: I'm not depressed at all. It only sucks that I can't talk and that I'm shaking. Other than that I feel really good. Mentally, that is. Yes... I liked to express my opinions, discuss ideas in a group… I don't do that anymore. Because I lose my train of thought after three sentences... I have to think about what I want to say first. If I have a thought about something, then I have to process how that thought will manifest in speech. That process is inhibited by my disease. By the time I've gone through all of this, I have lost track of the question.

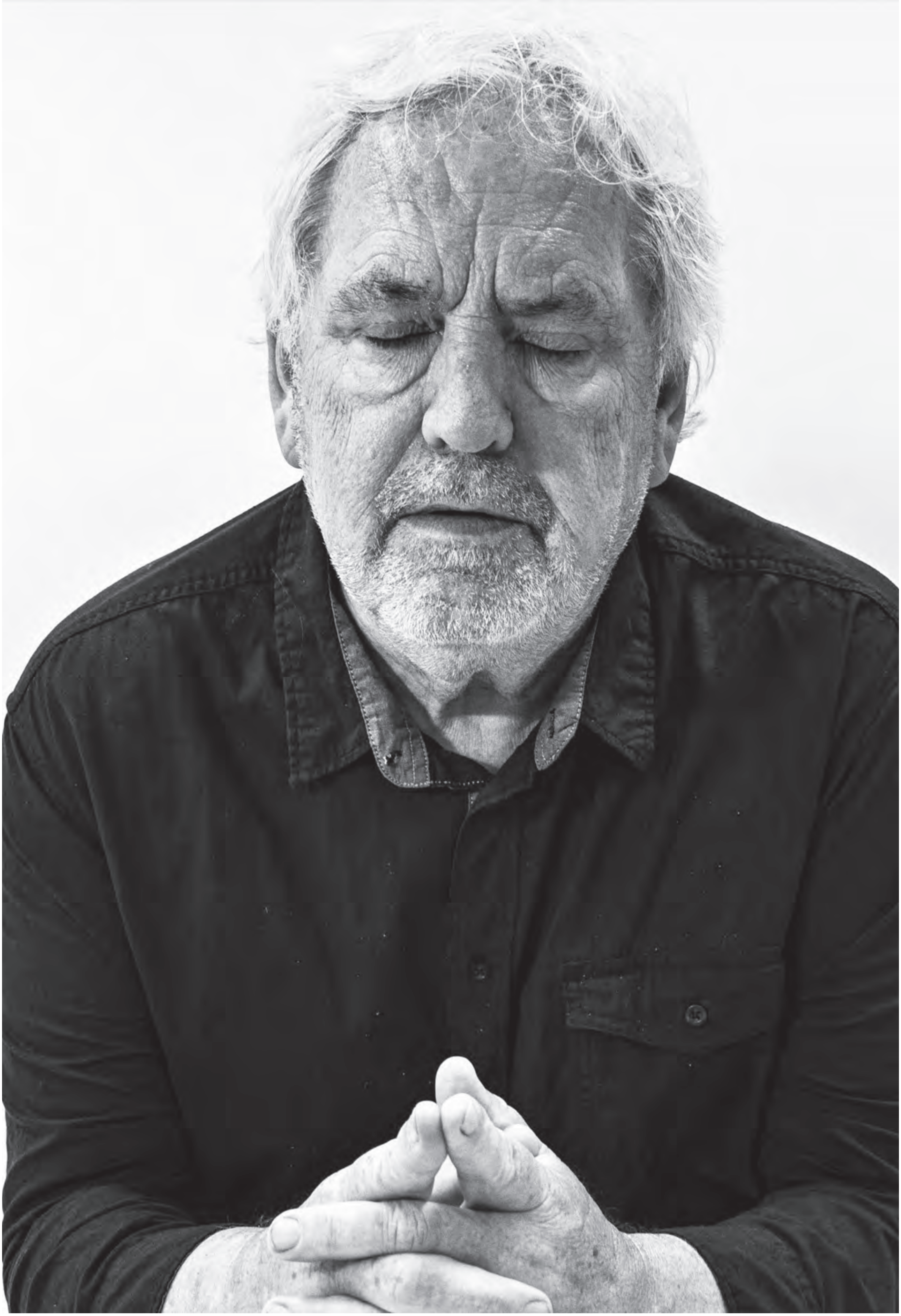
Margit: I think it's important to touch people. It was really difficult for me when touching wasn't allowed during the coronavirus pandemic. If I see someone is having a really hard time, touch can be very helpful. It's not explicitly taught as a means of communication in our training. But I think it is a feeling you inherently possess.

Margit: There is a click when someone genuinely listens to me when someone cares what happens to me and cares about who I am as a person. That is important to me.

Ernst-Daniël: This is my last performance. You're only as good as your last performance, they sometimes say. I don't believe in that. My play is about my fight against Parkinson's. It also contains stories about my own nursing training. I trained to be a nurse. I did it for a year and a half, and then I started singing. Found it a lot more fun anyway.

Margit: My father is a psychiatrist and I have always seen that he really enjoys his work, but I never thought that I would become a psychiatrist as well.

Margit: Well, the way I see person-centred care, and I think our department views it this way as well, is that you are interested in people. Someone comes in with their story. I think people have to cross a huge threshold before they come to us at all. What I also hear is that a lot of things have gone wrong. The first conversation can just be about the small things, it doesn't have to be all that deep.



(Re)viewing Person-centered Parkinson's care

Thieme Stap, Richard Grol

Seeing person-centred care, giving the people behind the ‘patient’ and the ‘care provider’ a voice, and gaining insight into their relationship: that is what this unique project is about.

I

For us as researchers and photographers, the process was at least as important as the result. Each time a pair entered our studio, everyone started to get a sense of each another. Who are you? Who are we? The person with Parkinson’s and the caregiver seemed to notice that this was a strange, new situation for us too. We had to let go of fixed roles, at least temporarily. And what we would find was not certain beforehand, but it gradually became clear throughout the process. It is precisely this uncertainty that makes this project unique and valuable.

What does it mean to put the human being centre stage? How do you gain insight into a care relationship through photographs? These questions immediately raised the fundamental quandary of what the added value of photography was for research and for improving healthcare practices. That is what we want to figure out in this short essay. To do so, we first delve into the history of photography, to see how its influence is thought about in healthcare. Then, we focus on the people being photographed and their relationship with the photographer. Finally, we look at the spectators, the viewers of the photograph, which brings us back to healthcare practice and research.

II

In his essay on “that very first and fledgling emergence of the world in black and white image” (De Jong 2017, p. 173), Oek de Jong describes the impact of the introduction of photography and how, because of its realism, it turned out to be something different than painting: “The photograph was something else. [...] The photograph brought something totally new: it was an image on which time was stopped and an eternal present was created” (p. 175). De Jong attempts to have us – we, who are used to Photoshop and Selfies – take on the perspective of a nineteenth-century observer who saw a ‘daguerreotype’ for the first time. In this way, he allows us to gain insight, perhaps even feel, what the “shocking experience of a hitherto unprecedented realism in the image” (p. 173) must have meant.

The idea that photographs are representations of reality also works its way into healthcare. The Dutch psychiatrist Pascal Sienaert sees that the value of the daguerreotype was primarily understood in functional terms (2014): it was suddenly possible to objectively “document psychopathological states.” Photography was therefore primarily used to “portray the illness, rather than the sick person” (p. 2). Photographs are primarily seen as “evidence”, writes Susan Sontag in her book On Photography (1973): “whatever we still doubt, seems to be proven as soon as we are shown a photograph of it” (p. 14). After all, taking a photograph is always a moment of non-intervention: “Someone who intervenes cannot register; someone who registers cannot intervene” (p. 22). This principle feigns as it were, a sense of objectivity.

Contrastingly, Sontag turns this proposition around (p. 107): “But since it was soon discovered that no two persons take the same photograph of the same object, the assumption that the camera provides an impersonal, objective image had to give way to the fact that photographs prove not only what is there, but also what a person sees, and therefore constitute not only a record but also an evaluation of the world.” Photography is not a clinical snapshot that captures reality, but rather an individual, personal perception; more specifically, an evaluation from the perspective of a photographer. Handling a camera may seem incompatible with intervention, but there is always a certain level of participation. After all, the photographer puts their own idea into the picture if only by ‘shooting’ the image at a chosen moment.

As a photographer, you make yourself complicit in everything that makes a subject interesting, including the suffering of others if that happens to be the subject, as in this book. Sontag calls this the ‘aggressiveness’ of photography: as a photographer you are the interpreter of reality, you have power. Sontag describes how the way someone is framed through photography could be seen as a political act.

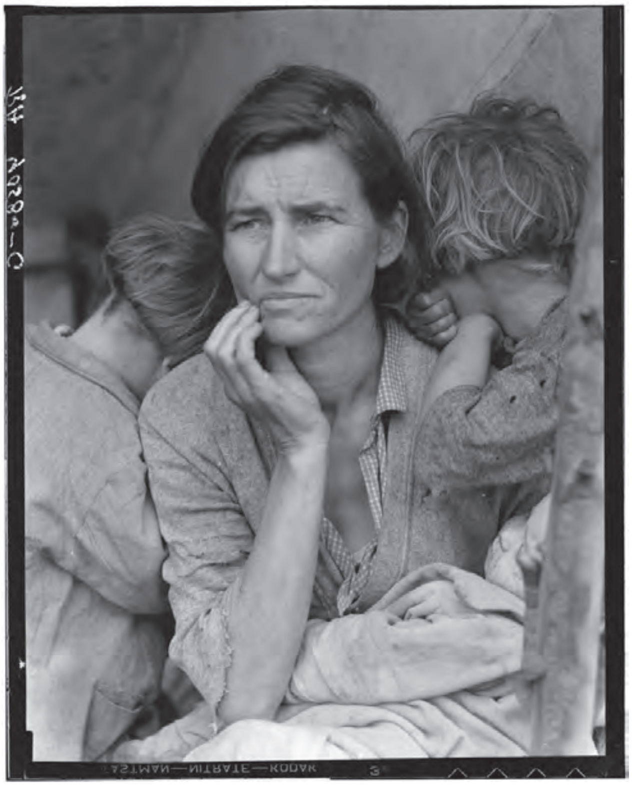
III

The relationship between photographer and subject plays a complex role in these photographs. A portrait addresses complicated aspects, such as the subject’s self-image and identity. The philosopher Roland Barthes calls this self-image the ‘pose’, the way an individual presents his or her identity. A portrait, so to speak, makes someone’s existence explicitly visible to the outside world. It is therefore important in the eyes of the person being portrayed how their identity is represented by way of images. This is why we have put so much emphasis on this aspect.

In portrait photography, various elements are important, such as the subject’s posture, their glance, the environment, the use of colour or black and white, the photographer’s point of view, the composition, and the lighting. In this way, the photographer communicates with viewers through the photographs. Sometimes there is cooperation, but usually, it is the photographer who directs the process. As the photographer Richard Avedon said, “we have different ambitions with an image.” For the model, it is about constructing self-image; the photographer usually aims to objectify and perhaps even to remove the mask of self-image. The intention is “to show the soul,” (Badger, 2007).

At the same time, of course, this is utterly impossible. An image does not show the ‘soul’, whatever that may be. When we look at the images in this book, we see people. Some of them are holding objects, others seem focused on each other, and others look directly into the camera. We see eyes, eyebrows, mouths. We see actions and sometimes we see the items the people are holding. But we don’t see a soul. So, what does Richard Avedon mean? Perhaps he means that the photographer’s snapshot is an appeal to the imagination of the beholder, thus creating a moment of attention.

A photographer offers a perspective that arouses interest; a timeless glimpse that you can relate to as an observer. It forms an opening in the facade of everyday life. Rineke Dijkstra, a famous Dutch photographer, portrayed vulnerable young people, such as mothers after giving birth or bullfighters after a fight. She says about her approach: “It is interesting when people show something that is beyond their control. I seek a balance between what people want to show of themselves and what they show in spite of themselves," (Phillips, 2012). We saw this a lot during our project: often during the photographing and the discussion about the photographs, that façade opened up a little.



Dorothy Lange's
'Migrant Mother', 1936

IV
Through that opening, you can look on as a beholder, maybe even decide, what you see in the photograph. Does someone present themselves as a patient with Parkinson's, as a professional specialised in Parkinson's, or as someone else? The photographer can, in turn, use his or her power in a dignified and appreciative way or stereotype and dehumanise. They can work in a negative way or in a positive and ethical manner. This brings us to the final perspective: that of the viewer and how photography can be used as an emancipatory tool.

Think of the photograph of the student facing the tank in Tiananmen Square in Beijing. At a glance, it seems clear what this photo stands for: the resistance of the individual against a system. It makes the photo a powerful political statement. The portraits in this book fit into the humane, documentarian style of the social reportages that German August Sander and American Walter Evans and Dorothea Lange made at the beginning of the twentieth century.

They had the emancipatory goal of collecting money for the poor – this is especially true of Lange and Evans. The aim of these photographers is to systematically present an image of society and thereby influence and stimulate opinion formation. In our project, the aim is to improve care and to stimulate person-centred care in Parkinson's disease in particular.

Etymologically, 'emancipation' means 'to take out of the hand'. In other words, 'to let go'. Paradoxically, photography seems to be a form of holding on, as the examples above illustrate: Lange and Evans wanted to record how bad poverty was and thus generate sympathy. In our project, too, we searched in an explorative yet methodical way for exemplary themes of person-centred care: involvement, the uniqueness of the individual, self-image, taking time, touch, and so on. However, this does not immediately show the emancipatory power of this research. Our pictures do not only want to convey but to create space for interpretation too. We have tried to create space for thinking about and engaging in person-centred care.

V

In an unusual environment, open and unexpected conversations emerged, from which the caregiver and the person with Parkinson's, as well as the photographer and researchers, learned a lot. Photography and care share a long history. Initially, this came from the conviction that photography brings a certain objectivity. Susan Sontag showed that the photographer's choices are also important. In the game between the photographer and models, unique glimpses emerge for spectators. Finally, we briefly explored the emancipatory power of photography: not for holding on but for letting go. We hope that the glimpses of person-centred care in this book will encourage reflection on this complex concept.

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Ann

& Ashley

Ann is a nurse and a photographer

She has had Parkinson's disease for some years.

Ashley is her physiotherapist.
Ashley is specialized in geriatric care,
and in Parkinson's disease more specifically.

Ann: You can capture everything with photography. As a child, I only wanted one thing: a camera. When I was about twelve years old, I bought a second-hand camera with all the dimes and quarters, and nickels I saved. From that moment on, I started taking pictures. My specialty was children's photography. I also took a lot of pictures of children in my studio. I would crawl around the child, taking photographs. But I can't do that anymore. I can't crawl around anymore.

Ann: First of all, Ashley gives me confidence and provides the right challenges. We focus on balance exercises. That's a big problem for me. Maintaining my balance. Physically, but also in terms of staying balanced in my life in general.

Ashley: You need confidence to successfully complete an exercise like this. I need Ann to confide in me, and I need to confide in her. If you trust each other then you're already halfway there.

Ann: I have worked in a nursing home. It means I have seen the end stages of Parkinson's. I thought to myself, 'Okay, so I have Parkinson's, but Parkinson's doesn't define me.' I have Parkinson's, but it's not who I am. So I have to figure out what I can still do despite my Parkinson's.

Ashley: Ann actually has the perfect coping style for dealing with Parkinson's, which is an active coping style. Not many people in her situation can say the same. It is a pleasant attitude to have. Ann is never angry or in a bad mood when she comes to our practice.

Ashley: I think it's very important when people come, that they don't simply do a series of exercises. I think it's important that they enjoy it and that I can motivate people to view the experience in a positive light. Parkinson's is quite an annoying condition. It's pretty intense if you have it. I think it's important to see how we can make the best of it.

Ann: If Ashley isn't doing well, I would certainly notice. I don't know if it's because I take pictures. I just observe a lot.

Ashley: People like to be heard. If you already have a trusting relationship, then your therapy is about fifty percent of the way there. If you don't trust the person you work with, then you aren't likely to accept what they say either. Then touching might already be a thing.

Ann: I don't know what Ashley's home situation is, but I do see how she deals with me and how she deals with other people. What I see is Ashley being involved and dedicated: I see a person who I can gladly surrender to. We have an amicable relationship.

Annelien

& Nienke

Annelien is a doctor and a researcher

Owing to a frozen shoulder, Annelien found out that she had Parkinson's in 2016.

Nienke is her physiotherapist. They find common ground in their passion for sports and their sense of perseverance.

Nienke: My name is Nienke, and I am a physiotherapist. So I get to be who I am. Of course, I let some people get closer to me more quickly than others.

Annelien: I was looking for a new physiotherapist, and I saw Nienke's picture and thought: she looks tough. And sure enough, she gave me exercises to do every day that immediately started stretching my arm. It hurt like hell. But it did help right away. I got rid of the frozen shoulder in six weeks.

Annelien: You only have half an hour in the consulting room. You talk a lot, but I didn't know all this about her.

Nienke: My job is to motivate people, to get them to do something they don't want to or can't do. Even when people come in with a backache I say, 'I'm not just going to massage you: we're going to train.' I'm very honest! If I think something won't work, then I will say: 'Let's choose a goal that's a little more achievable.'

Annelien: I always wanted to run a marathon. I discussed it with you and you said, 'Of course, you can.'

Nienke: I did think to myself, 'I do hope she can do it.'

Annelien: Oh, but you never said that!

Nienke: Yes, but if I said it, it might not have happened!

Annelien: You were the only one who told me I could do it unconditionally. It helped tremendously. ‘Sure,’ she said. ‘And if you can run a marathon, you can also get through a pregnancy.’

Annelien: To the people around you, you’ll never be who you were before. To yourself, you’re still the same person, and you can do everything you could do, and you want everything in life to remain the same. But to the people around you, you are kind of limited.

Nienke: People think in terms of limitations. I always think, ‘You have this, but you can always approach things differently. And act with love.’ I really love that part of my job.

Annelien: I am convinced that there should be a centre where you can go to inspire each other. Where you can play sports together. Sports are key in Parkinson’s.

Annelien: My father got the diagnosis three months before I did. You could clearly see it in him and I joked with him, like, ‘I have that too.’ He then said, ‘Don’t joke about that. It’s not funny at all.’


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Ronnie

& Marjan

Ronnie was a social worker

He has had Parkinson's for ten years.
He got it when he was 48.

Marjan specialises in Parkinson's disease.
Ronnie entered Marjan's waiting room because
he was having depressive thoughts.
During this photography session, they got to
know each other a little bit better.

Ronnie: I have pictures of me as Saint Nicholas; this is the ring that Saint Nicholas had. I went to school with it. It's gigantic for a child.

Ronnie: The GP couldn't find anything amiss and sent me to the neurologist in Doetinchem. He couldn't find anything either. So he said that I should go to Nijmegen. Within half an hour I was out the door: Parkinson's.

Marjan: As a professional or as a psychologist, you don't get a full impression of a person all that quickly. If someone were to lay everything out in front of you and say, 'Look, this is me, here, This is my life, this is my background,' that would work. I knew some things, but definitely not everything. We need to make decisions in the conversations we have. The focus is mainly on the problems you come in with. I know the rough outline, but not all the details.

Ronnie: I had guitar lessons. Didn't go well. I stopped at a certain point. Well, I like being creative because I work with people with intellectual disabilities.

Marjan: I also really adore nature. I love going for walks or finding peace and quiet in nature. The object I brought, a butterfly, signifies a whole process of transformation. A butterfly is first a caterpillar, then pupates and you get a beautiful butterfly. The caterpillar is constantly changing, which is what I think is so beautiful about nature, and about people.

Ronnie: I do keep in mind that my working career is pretty much over. Not over in terms of doing volunteering work, for example, but I mean, working for a boss and having work pressure is over.

Marjan: You know, touching is very natural. Over in the past year, of course, I have had to keep a distance of a metre and a half. I do not think we should have to keep this distance forever, particularly if we want to connect with people. That's not to say that you always have to touch, but sometimes you need it, even if it's just a pat on the back. With some clients, you have to keep your distance. That's also true.

Ronnie: I was born and raised in the Achterhoek. You could do all kinds of things there: light fires, catch fish, crayfish, and salamanders. There were meadows as far as the eye could see. I mean, I'd come out of school, I'd drink a glass of squash, milk, tea or coffee and then go outside to play. The whole neighbourhood was always crowded with children. You don't see children playing in the streets anymore.

Marjan: In the beginning, I never thought about clients' stories after work, but it was more like, have I done everything right? Certainly, when I started, this thought stuck with me. Fortunately, over the years, it has diminished with experience. You really only learn by doing, and with a lot of support and supervision.

Ronnie: I'm actually finding out more about my therapist now. It does give me some peace of mind to know that, gosh, there is a person behind the psychologist trying to help solve my problems and point me in the right direction. I have a bit of background information now, so my trust in her has only grown.


Mary's Boy Child
Oh My Lord
Boney

Rob

& Jacco

Rob has sold and developed paint for years, alongside working for a large chemical company

He has had Parkinson's since 2019 but showed symptoms before then.

Rob has started to work less, and Jacco, his occupational physician, is helping him with the process.

Jacco: I have been working here as an occupational physician for fifteen years. We don't only deal with absenteeism. Fortunately, it doesn't happen very often, but accidents can happen, and the medical service is called in when it does, and quickly at that. We do travel medicine too. I'm also the tropical doctor here for people who travel for business, but for private trips too. Thanks to the physiotherapist and the social worker being in-house, we get to know the people very well.

Rob: Cor, a colleague of mine fell off his bike. However, thanks to the gentleman here on my right who said: 'I'm not going to let him go, he's going to the hospital!', we discovered there was a little more going on than a simple fall. It turned out that he had a heart condition. Then you clearly see the role and value of occupational health services.

Rob: Yvette from human resources once brought me something, and she said to me in passing: 'Rob, I can see that you are tired. You do everything in slow motion.' My wife had used those exact same words too. So I came home and said we needed to see a GP.

Jacco: You know, I've always been very athletically inclined. Even when I was just a boy, I played soccer because there wasn't much else to do.

Rob: When I first went to see my GP, he made me an appointment to see the neurologist in August. The neurologist said to me: 'I don't know yet. But we're going to exclude things: make a scan and then we can say you don't have a tumour, you don't have a blood clot, etcetera.' The likelihood that you have Parkinson's, of course, increases with the exclusion of every other diagnosis. Then he said, 'Let's wait until January then we can see if it gets any worse.' It got worse.

Jacco: My wife works as a physiotherapist in the hospital, not in a primary care practice, but here, at Rijnstate Hospital. My daughter has also started studying physiotherapy – she's in her second year. She only comes home some weekends, but then we talk about it a lot, of course.

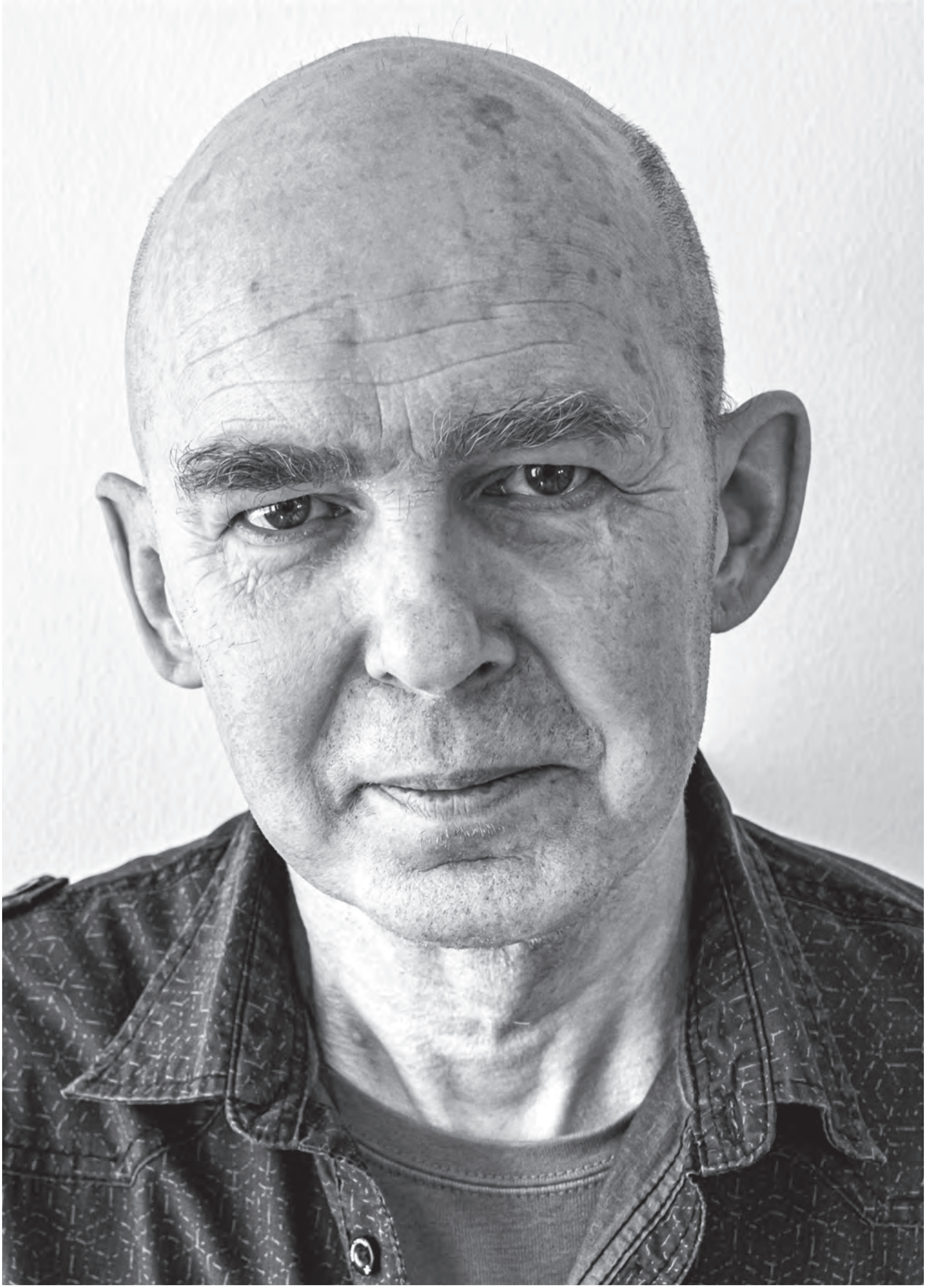
Rob: After some time, Yvette from HR made clear it was a good idea that I work four, eight-hour days and stick to that because I still need to have energy after work. You can put all your energy into your work, but then you'll come home too tired.

Rob: My speech-therapist was sitting across from us and said, 'The three of you have Parkinson's.' 'Three?!' 'Yes, Sonja, Rob, but Mr. Parkinson's is also sitting here.' I thought that was a very nice way of looking at things.

Rob: When I started the levodopa the second time, my facial expressions changed. You can see it in the picture.

Jacco: In the past, as an occupational physician, you often had consultations lasting ten minutes and you would do six in an hour. That's pretty normal as a GP, but as an occupational physician, you have to do a lot of different stuff in those ten minutes. It used to come down to a single question: can this person work?

Rob: Everyone who goes to Jacco knows that they will be treated in a humane, pleasant way. Maybe that's not the right wording, what I mean is you present yourself in a particular way, as someone who encourages others and looks at the bigger picture.



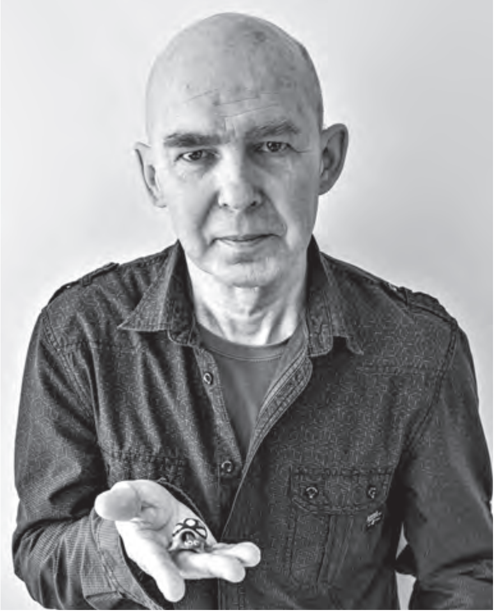
Joshua

& Martha

Joshua likes to compare himself to a tortoise

Joshua has had a variety of professions and has had Parkinson's disease for about nine years.

Martha has worked in different roles in the care process that they have designed together. At first, she was his Parkinson's specialised nurse. Later she became his care coach.



Joshua: Martha does not have Parkinson's. She can rely on herself and take initiative. Parkinson's kind of robs me of that. I need structure. If that structure is not there, I'm alone. Without that structure, I just won't make it.

Martha: I think people want things to be different, but they just can't do it themselves. I think that's true in every organisation. Well, maybe it's not about not wanting change. Managers want change, but they cannot make the change.

Joshua: When I was diagnosed with Parkinson's, it was quite a shock. But at a certain point, I was like: I'm a tortoise now but being a tortoise also has some positive points. Tortoises are very slow. Tortoises are also wise, but you have to be patient. At some point, I started to see that Parkinson's isn't all bad.

Martha: Joshua also senses when something is wrong with me. So, if there's something going on with my kids and I come in, he can sense that. So he'll ask me what's up, and that's how open we are with each other.

Joshua: For me, the concept of time has become different since I have Parkinson's. I need a lot more time to get my life in order because my brain just works differently. I just need more time.

Martha: This does say something about me because touching another person comes very naturally to me. As is allowing yourself to be touched, that's the other side to it. Joshua touches literally and figuratively. Joshua touches me too. It shouldn't take me by surprise.

Joshua: Martha has a tactile way of making contact, I think. I only do that with people with whom I feel safe. And, well, you're going through this process with each other. It's not just: I have to sense your movements in order to go somewhere. We have to do it together. That's what I mean by dancing – we both adapt to each other. And then, once you get into a rhythm with one another, then you can really start to accomplish things.

What is here now

Jur Koksma

You see the elongated drops fall from the teeth, like melting icicles on a roof edge. There is no scream. Only Janet Leigh's wide-open gaping mouth. You've seen this scene a hundred times. You are seeing it now for the first time. The rings of the shower curtain dance with hypnotic motion. It feels good to be able to watch so quietly, time flowing past you and you, yourself, immersed in what is here now.

24 Hour Psycho is a 1993 video artwork by Douglas Gordon. By slowing down the rendering of Alfred Hitchcock's masterpiece Psycho 13.21 times, each frame takes about half a second. If you want to see the entire film at this pace, you will need – as the title of the artwork promises – exactly twenty-four hours to do so. With one simple intervention, Gordon creates art out of 'the art of looking.'

Good care starts with looking carefully. William Osler, one of the founders of modern medicine, claimed that of all the things a doctor must learn, the art of looking was the hardest to master. He was not just concerned with making the correct diagnosis: he argued that a good doctor focuses not on the disease, but on the person who is ill. Osler is often quoted, but more than a century after his death, his advice proves as relevant as ever.

'In view of the time' is usually an announcement of closure, but for adopting a different view on time, seeing may be crucial. For seeing something else, for seeing another, you cannot rush. And yet, time is elastic. In Douglas Gordon's artwork, half a second becomes an eternity, while ten minutes can pass in an instant. At least, sometimes they can. When you're at the doctor's, for example. Time breathes down your neck. 'Wait a minute,' you think, 'not so fast.' But the consulting room is not a waiting room. In an American study, researchers found that on average, doctors interrupted their patient's stories after a mere eleven seconds (Ospina et al., 2019). Those doctors had apparently already seen everything, heard everything. In this way, the doctor's office is not a place that makes you feel seen.

For a number of years now, there has been a programme at Radboudumc in Nijmegen for doctors to learn from the way artists look, think, and act ('The Art of Seeing'; Koksma et al., 2017; Van Woezik et al., 2021; 2023). For seven Saturdays in a row, forty students visit artists in their studios and immerse themselves in artistic practice. Participants indicate that the programme makes a deep impression on them. Time is an important factor in this in four ways. First, the prolonged duration of the programme: seven weeks. Second, the conscious decision to take all the time – the whole day – for what you are doing. Third, the viewing exercises each have their own temporal designs. Fourth, participants were given ample time to reflect on their experiences, record them in a notebook and discuss them with others.

Ten minutes of consultation, ten minutes of looking at a painting, or ten minutes of drawing: the experience of time is completely different. When we gave doctors ten minutes to describe a painting 'as well as they could', they listed what they could see on the canvas.

When we put the same question to a group of nurses and another of elementary school teachers, they came back with something different: an atmospheric description of the entire picture, including feelings they had about it. Apparently, what you see and how you look has something to do with the work you do. Doctors who participated in 'The Art of Seeing' discovered their medical training shaped how they saw, and that even their feelings played a major role in it.

Like Gordon's artwork, the photographs in this book aim to invite closer observation. Narrative has a decisive role to play in this. In 24 Hour Psycho, we get the chance to look differently because the story that we already know, the plot of Hitchcock's film, sinks into stretched time. The stained glass image that colours our gaze is removed. What remains is space for another story. In this book – and in the research that lies beneath it – image and text play a game to create a similar openness. Our eyes move back and forth between image and text, our very browsing has a temporal dimension. As we gradually come to understand more about the lives of those portrayed, we become aware that what we see changes every time we take a closer look. The images do not illustrate anything, and the texts do not intend to illuminate. Like a love couple in a Bollywood movie, they dance around each other, attract and repel each other. There is no final kiss and nor should there be. Nothing needs to be redeemed or made right. Instead, it's about speaking to our imagination.

Photography, in a sense, is reductive, given that it solidifies reality into a single image, to a temporal zero. The film comes to a complete standstill. However, our photographs do not seek to represent, they do not capture any presupposed essence of person-centred Parkinson's care. These photographs present, they present the dynamics of the relationship between the person of caregiver and the person living with a chronic condition. If these photographs come to life, they do so if somehow, as if by magic, a connection of compassion links the viewer's life with that of the person portrayed. That connection is what photography may construct. In the end, what happened in the photo sessions, for the most part, cannot be transferred and the true memories of it belong to the people who were present alone. Taking time was central to this. Those portrayed had a full hour to engage in conversation about what really mattered to them in person-centred care. There was time to listen to each other's stories, and without exception, both interlocutors came to understand fundamental things about each other that had not emerged before in their often long-standing relationship. Within narrative medicine, there is often an ardent plea for "slow medicine" (Charon, 2008), and for good reason.

Making time offers space for stories. Making space creates the possibility of taking time. Space, in our project, is a way of being together in an hour of precious time. Looking at the photographs themselves, space is also a huge roll of white paper rolled out behind the models. Space is light from a north-facing window or from a lamp off-screen. Space is answering a question with a question. Space in this book is the turning of the page. Each image has a support, a copper plate, a phone screen, a rock wall, a canvas, and supports have frames. Allowing for a lot of blank space, the frame in our photographs holds itself up unassumingly at the edges of the paper.

Douglas Gordon, stills from 24 Hours Psycho, 1993

A frame defines the difference between that which is the case and that which is not. A frame legitimises. The unadorned framing of our photographs questions this legitimacy. As we can infer from the differences in viewing between different professions, we do not see the world as it is, but in relation to the frames of thinking in our heads. When we talk about person-centred care, do we really know what we are talking about? What is the actual problem? Here, we encounter a fundamental issue: the way of thinking about this problem is part of the problem, and part of that way of thinking is that the way of thinking is often not questioned at all.

The author David Foster Wallace warned Kenyon College graduates during his commencement speech that learning how to think only begins in real life, and it requires constant attention: “Learning how to think really means learning how to exercise some control over how and what you think. It means being conscious and aware enough to choose what you pay attention to and to choose how you construct meaning from experience.”

What can photography offer us in this? “Writing about music,” says Cuban novelist and musicologist Alejo Carpentier, “is like dancing about architecture.” What can one language say about another? What images speak of is ineffable, but that does not make the conversation about them any less relevant nor, for that matter, does it make them inaccessible to scientific research. The paradoxical challenge of improving person-centred care is that you have to step back to get closer. Straight to the goal is not the way to get there. There is no ‘there’ there. ‘There’ is a here that we have trouble seeing. We move forward by slowing down. Person-centred care only happens when people are mindful of what is here now.

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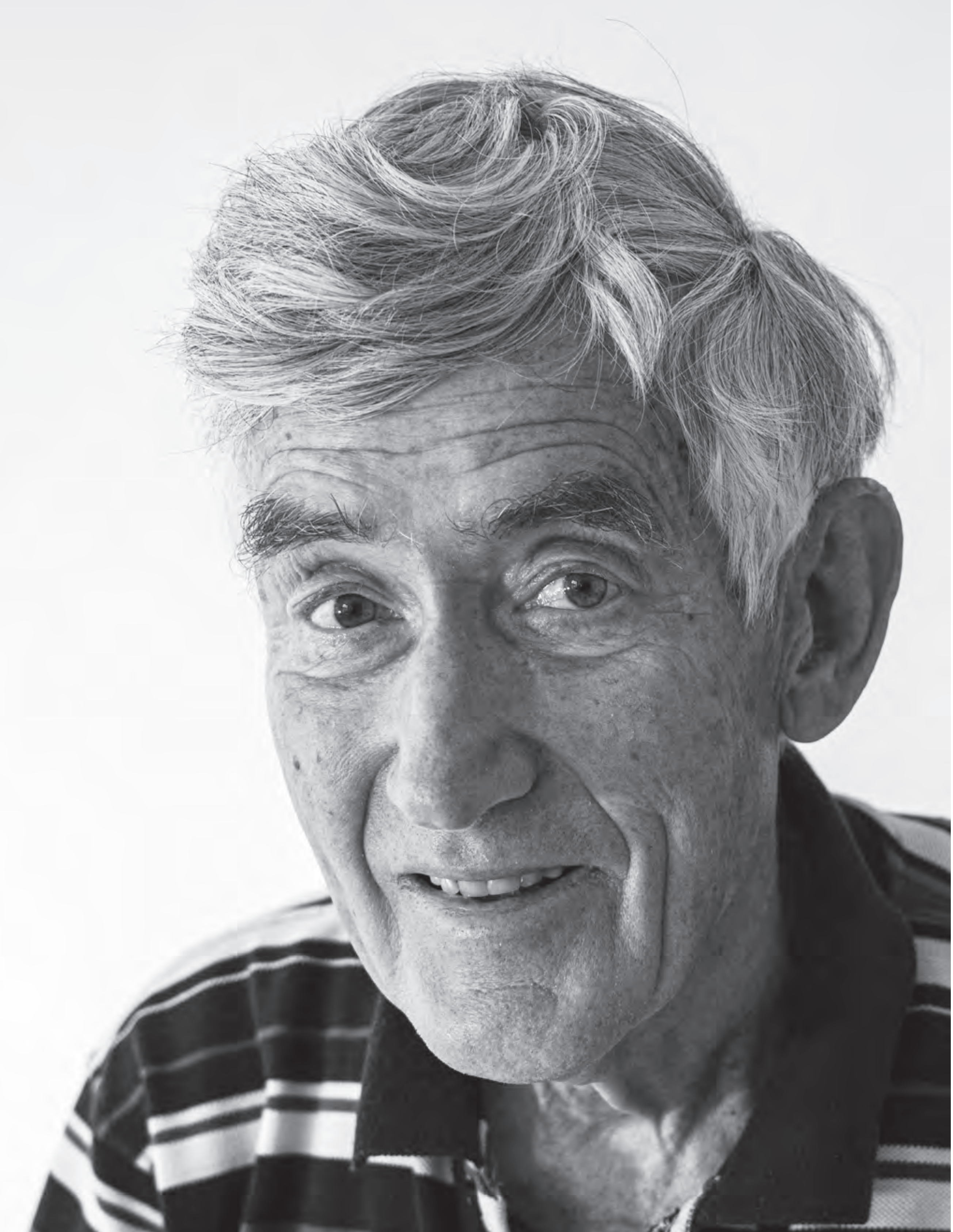

Bert

& Emiel

Bert has a great voice

Bert has Parkinson's since 2015.

Emiel is Bert's speech therapist, but he is also the conductor of the Parkinson's choir Bert is a member of.

Bert: I come from a very musical family, at least, on my mother's side. A big family with musicians, organists, singers too. I would say that I was brought up with it, but I never wanted to or could make a profession out of it. I stuck to playing the piano. The annoying thing is that my ability to play has diminished considerably.

Emiel: Music is a large part of my life. In the last six or seven years, I have started conducting. I have a choir for Parkinson's patients, and I've enlisted Bert to take part in it. I never actually use this baton because it's only for conducting full orchestras.

Bert: You get hoarse more quickly with Parkinson's, especially if you are stressed. These circumstances are also stressful. You notice that too.

Emiel: You notice that as you get older, your voice loses depth. It has to do with age and because you're a man. Parkinson's disease adds to it. I think you're actually doing very well. But you do lose some of your low registers. Bert always sings bass. Well, last year, you were more of a baritone, right? You don't lose the high notes.

Emiel: Apparently, I also like to lead a little, although leading often also involves a certain degree of, what shall we call it, being a little stricter. I always find that difficult. I try to solve this by keeping the momentum going so people don't get a chance to interject.

Bert: I would say my wife is also part of the care process, of course. Not only in terms of providing care, but she also keeps me in the loop. Constantly letting me know what she thinks.

Emiel: I only know nice Parkinson's patients, and I have noticed that I also really enjoy working with people who have Parkinson's. I always try to create a pleasant atmosphere when caring for people. I'm always looking for ways to connect with them.

Bert: It's amazing that I can still play tennis so easily. I was never a gifted player. I did not depend on technique but on my dedication, and that remains that way. It's nice to know that not everything is doom and gloom.

Emiel: What you often notice is that people with Parkinson's tend to slow down in a group discussion. They want to respond to something, but everyone else has already moved on to a different topic.

Bert: One of my grandchildren made a book of the stories I told them. Can I read you one? 'Once upon a time, there was a little boy named Jaap. His parents had a cargo boat with which they transported all kinds of things to Germany over the Rhine. They did everything together, and they were on the boat all year round. Even when his mother got pregnant, they still stayed on the boat. The midwife came on board to deliver the baby, so Jaap stayed on the boat all the time. His box was on top of the roof of the cabin when the weather was nice and Jaap would get very excited. When Jaap was a bit bigger, he learned to swim on a long leash. This meant he could swim separately from the boat, and whenever they passed the village of Waalzicht, Jaap's father would sound the ship's horn three times and then grandpa would hurry to the dike to wave at them.'

Xander

& Bart

Xander works at an architecture and engineering firm

He has had Parkinson's since 2011.
He was 42 at that time.

Bart is his neurologist. Together, they thought about how they could make a space for people who have Young Onset Parkinson's disease (YOPPERS). It is currently a well-known concept within the Dutch Parkinson's care landscape.

Xander: The disease is slowly progressing. At the moment. I'm in the grey zone between not working anymore and maybe still working, but not really. I'm a technical installations consultant at an architecture and engineering firm. It used to be an external job, so I often went to construction sites and meetings. Now it has actually turned into an internal one, more about guiding people and processes.

Bart: Creativity? Yes. My mother is a sculptor, and my father draws and does theatre. He performed with Herman van Veen, but in the end, he didn't dare take the step to earn his money that way. He felt he wasn't good enough, so he became a teacher. But he's always been very creative.

Bart: We started a project together about caring for young people and how to make their care more person-centred. We're definitely going to talk about that here!

Xander: Bike for Parkinson's marks the beginning of our relationship. Bart asked about the impact of the diagnosis on your life. During a 60 km cycle, I explained what the impact is, and that it goes further than, say, the external factors of the tremors and taking pills. It particularly hinges on the invisible side and all of the aspects that are associated with it.

Xander: It is easier to draw and paint than use a computer and words. I find it easier to remember images than, say, written text. I also believe that a picture is worth a thousand words, so to speak.

Xander: Brushes are actually very odd things. I see myself in them in a way. They are very expressive, but very ordinary too. The handles are made from wood and are quite stiff. However, the heads are very flexible and you can do all sorts of things with them. They are suitable for different media as well, for paint, ink, or whatever else you can think of.

Bart: So, my question was whether it is true that it's different to have Parkinson's when you're young compared to when you're retired? What you said was very clear: 'Yes! I struggle with a lot more than just slowness, stiffness, and trembling because I have managed to get that under control now. But what about my children, my wife, and work?'

Xander: At home, they pay attention to whether I'm working for too long and, at a certain point you just have to say okay, this is where I draw the line. I actually noticed that I was overcompensating for what I didn't get done during the day.

Bart: I was taught that there is a doctor and a patient, and that there is a certain hierarchy. But my mentor, Hans Speelman at the AMC, sent me back to patients if I didn't know their story.

Xander: Often you get socially desirable answers, you know? 'No, my relationship is still fine, nothing has changed!' My view is that there has definitely been some change because there is an additional concern now: the diagnosis. It's difficult to prepare for something like that. It brings a huge amount of uncertainty with it, which weighs on a relationship. What helped me the most was that LEAFS (support group) validated me in all the ideas that I had.

Bart: I was on an X-team with Jur, and Stine Jensen walked in, gave a talk, and said that person-centred care was a pleonasm. I thought hey, finally someone says it like it is: a load of bullshit! Person-centred care is just a combination of words. Of course, it's about people – o why are we even talking about this? Why does it need to be advertised?

Bart: I think that care professionals still have a lot to learn. The most practical example: well, the motor deficiencies you can see quite well, but with Parkinson's disease, it is what you don't see that causes the most issues. So I think what we do here now is really very good.


MAGURA
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Louis

& Carla

Louis was a physiotherapist who focused a lot on people with Parkinson's

Louis and Carla have known each other from before Louis was diagnosed with Parkinson's.

Carla is a neurologist and has also been Louis' neurologist for about four years now.

Louis: Now that I am a Parkinson's patient myself, I notice that if the surroundings are favourable, my body functions better.

Carla: You have a role: you are a doctor or a physiotherapist. But you are also a human being, so you have to reconcile the two somewhere. That makes your human side feel good. And maybe that's true for your doctor's side as well, but I think it mainly makes you feel good as a person. The fact that you can still remain true to yourself and don't disappear completely into your role, that is.

Carla: When you were a physiotherapist, you often saw patients every week. Sometimes you said, 'I'm worried about your home situation' or 'I'm worried about your loved ones because they seem to be overburdened.' That's nice to hear, as a doctor.

Louis: We discussed whether I would go by myself today. I can do it alone, but what I've noticed in the last few years of having Parkinson's is that sometimes I don't tell the whole story. I don't hold back on purpose, but I paint a coloured picture, as I can only describe things from my own point of view, and then my wife's version of events is more objective.

Louis: I wanted to study and work in forestry and then became a physiotherapist, which is something quite different. However, if I have to characterise myself, I am actually a bit of a loner. I do find contact very important, but I can do very well on my own. I am a bit of an 'Einzelgänger'.

Carla: Well, I'm perfectly fine being by myself as well. Put me in a hut on top of a mountain and I'm the happiest I can be. I'd study philosophy. Being able to combine philosophy and nature would make me very happy. So I brought this book by Nan Shepherd. If she were to describe a simple flower, she would write a whole page about it. It's so beautiful.

Carla: I didn’t go to medical school to become a doctor, oddly enough. I never realised that becoming a doctor was the logical conclusion. I thought the human body was interesting, I liked biology and I thought, well, I guess I could do that too. There were a lot of farmers in my family. They weren’t allowed to study, so I don’t come from a highly educated family. I think I was the first one in the family to go to university.

Carla: We are a teaching hospital. Some residents are very good: they can see the people behind the clinical pictures. But this skill- isn’t inherent. At the start, you’re happy if you can just come up with a diagnosis or a treatment plan.

Louis: If I were to go to a physiotherapist now, and they were to ask me to do two tasks, I would not come back. The satisfaction of completing a single task for me is greater than two. So, if I were to walk over with a cup of coffee in my hand, and I put that cup of coffee on the table, walk back, and then grab another cup of coffee, the satisfaction would be greater than if I were to shuffle with two cups of coffee on a tray, and think ‘Whew, I’ve made it.’ The interesting thing is that you arrive at different insights as a patient yourself than if you were a professional.

Gerard

& Jacqueline

Gerard is a retired army colonel

Gerard has had Parkinson's for two years.
He found out he had Parkinson's because playing the piano became more difficult.

Jacqueline is his physiotherapist.
She specialised in Parkinson's care.

Jacqueline: Initially, I chose to become a physiotherapist to help others. Then I started to experience how great it feels to move.

Gerard: They call it a disease, but it's actually more of a handicap, consisting of multiple different facets. For me, that handicap gradually started to manifest a few years ago.

Gerard: My stamina is just fine. And yes, I shouldn't have any illusions about that because it's only going to get worse. But that's not the heart of the matter. You have to be able to keep going. That's what it's about. Whether you do it well or badly is another matter, but doing it is important.

Jacqueline: Gerard likes to go deep and see what he can get out of the therapy. With other people, I determine if they can handle it. Not everyone can.

Jacqueline: Playing golf is important to him. That became clear to me when he visited me for the first time. But the fact that he likes to play the piano as well, I didn't know yet.

Gerard: I have discovered that you have to put everything into perspective. Because I'm not ill in the sense that I don't have a fever and am not in any severe pain, I'm able to deal with it in a more humorous way. Then if something doesn't work out the way I thought it would during physical therapy practice, I can take it lightly.

Gerard: I don't necessarily have to be in charge. I carry out the exercises and sometimes I say, 'God, not today' because it's just a bit too much. But that's all I'm aiming for.

Jacqueline: It was clear the first time we met; the fact that Gerard likes to be in control of his body. He notices that he functions better now, and that practice has given him greater control over his movement.

Gerard: I should also say this: the Parkinson's care organization is actually very good. It may serve as an example for other care organisations for other diseases. There's a ParkinsonNet, a Parkinson's association, a Parkinson's café, Parkinson's TV. It's incredible, all kinds of places you can get information from. So yeah, it's pretty good.

Gerard: The app is very good at bridging the gap between care and the patient. For example, if I have a problem, then a dietician, a Parkinson's specialist, and Jacqueline can contact each other in an app; they can talk about it and arrive at actual, concrete actions. It means problems actually get solved.

Gerard: It takes me weeks to get a piece by Chopin under control. Four pages take me months. Physically, I can't play anymore because the tremors have gotten worse. I have to wait until my fingers are fully on the keys before I can play the notes.

Dominique

& Leonore

Dominique writes about her life with Mrs. P

Dominique has had Parkinson's for three years.
She is a journalist by profession, so she decided to
write a book about it: The uneasy lessons by Mrs. P.
Over the last few years, she has taught yoga,
focussing on people with Parkinson's.

Leonore is her Parkinson-specialised nurse practitioner.

Dominique: What I really like about Leonore is that she does not look down at you, but she is there with you. But not in a pitying way. Do you know what I mean? If you notice that someone feels sorry for you, then the relationship quickly starts to feel unequal. She doesn't trivialise, but she just thinks with me in a very down-to-earth way: 'Oh, what can you do with this,' or 'Oh, what can you do with that?' If I compare it to the contact I had with the neurologist, I feel like he is a kind man, but much more business-oriented. Leonore tells me that if I have a question, a problem or anything at all, I can email or ring her any time. The neurologist would not likely do the same.

Leonore: It's very funny to see what kinds of conversation develop. And yeah, I just really like it. I've actually only seen Dominique a few times. I think I've seen her two or three times professionally, and I've also met her at her book launch. I thought it was really special that we could have such an open and equal conversation.

Dominique: In any case, it's very cool that the topic of person-centred Parkinson's care is being addressed broadly. Because, you know, I'm noticing more and more that the stereotypical Parkinson's patient doesn't really exist. I think it's an important lesson for me.

Leonore: She showed me a natural form of acceptance. How do you deal with a disease that never goes away? Perhaps writing her book has helped her to come to terms with it all. I think it is really very clever. There is also a stark contrast between how Parkinson's is perceived and what it is like in reality, and that sometimes irritates me: the image of the warrior fighting the disease.

Dominique: When my brother was diagnosed with cancer, he already had metastases in his lungs. They tried chemo – everything. But I've learned that once there are metastases, it's pretty much impossible to get rid of them, no matter how you try. He really lived life to the fullest in that last year and a half. For me, it really was a learning experience: okay, bad things can happen to you, but this may also encourage you to live life more intensely. Not in the sense of making a difference to the world and having your name remembered, but I do appreciate living more.

Leonore: I have learned that I can give a little more with that personal touch.

Dominique: I really can't see Parkinson's in a negative light. Sometimes I see social media posts saying things like, 'It's a shitty disease that just takes things away from you every day.' I wholeheartedly disagree.

Leonore: You can overcome most obstacles: you just have to know how. I think some people find that difficult to accept. I often ask, 'What is most important to you?'

Dominique: I know I have Parkinson's because of my neighbour. He's going to turn 87 soon. He's really a wonderful man. He still messages me sometimes, 'Hey neighbour, how about a drink?' Isn't that great for an 86-year-old? He told us he had Parkinson's disease. We didn't really know what it was, so we started googling. I ended up saying, 'Haha, well, I think I have it too.' I saw a list of symptoms that I recognised. The only thing was, I was 49 at the time.

Leonore: Well, if I had to visualise it, then I would say you're driving towards an endpoint, but I take side roads. I don't always go straight to my destination. There are other roads that lead to Rome.

Dominique: I always find it strange to look at myself in pictures. I find it strange because I don't see myself that way. I find that one very powerful, for instance. And you can tell that we have fun together.

Falling and the Art of Change

Mieke Moor

First, before I started to write, I looked. I looked at the photographs of Parkinson's patients and their caregivers, and I looked at the moving images of Le Sacre du Printemps, the ballet by the choreographer Pina Bausch at the same time.

I must have been searching for a combination of still and moving images unconsciously because something in the Parkinson's photos struck me: they seemed so 'vertical'. What I mean is that both people in many of the photos are upright. Bodies erect, backs straight. It reminded me of what the dancer Jo Ann Endicott said about the main challenge of playing the lead character in Le Sacre: being able to fall. The entire performance works towards the climax of falling. There is a small, red-coloured booklet, titled Dossier, in which Endicott explains the difficulty of falling in a dance tradition that is preoccupied with reaching for height. Going against the grain, Endicott highlights the importance of falling. I had never thought about it before[1].

Evidently, for Parkinson's patients, falling represents a danger and a risk; it follows that Parkinson's care focuses on staying steady and keeping a balance. The photographs in this book show patients practicing that very act. Paradoxically, living with a chronic condition also means letting go of what used to be reassuring – good health and freedom of movement. It means finding a new position in life, learning to accept the frailty of existence, and allowing other people to help you.

What I have asked myself is how could the concept of falling be meaningful in a process of change. And how, therein, can others be of help? To address these questions, I will turn to the story of Le Sacre du Printemps, an ancient story retold, and to Pina Bausch's method of working in relation to the dancers, and to Endicott's experiences. I will try to make connections with the images and words of people living with Parkinson's. In a way, my approach resembles a falling motion: rather than building, the very idea fell to me, and exploring it further warrants self-reflection: should I allow myself to just fall into it, like Alice into the rabbit-hole?

The Sacrifice

The famous ballet Le Sacre du Printemps tells the story of a young virgin who needs to be sacrificed to appease the Earth goddess so the goddess will allow the beginning of spring. It takes quite a while before it becomes clear who among the dancers has been chosen. Fate is symbolised as a red dress. The dancers anxiously pick the red dress up from the floor only to start panicking, and they throw it away immediately. It is a constant battle between fear and honour. The performance pivots on the contradictory nature of the one who is to be sacrificed: she is glorified by all, they carry her like they carry their fate in their own hands, but she must fall in the end. Seeing her inner struggle makes the audience experience the primal conflict between life and death. This tension is also tangible in Igor Stravinsky's music, where harmony is hard to find, and the rousing rhythm takes you to somewhere perhaps you would rather not be.

The Dancer

Jo Ann Endicott performed the lead role of the sacrificed virgin in Pina Bausch's Sacre. She shared her experience with falling from a dancer's perspective. Her training as a classical dancer had taught her to make her every move seem light and effortless. This prevented her from falling as the story needed her to. Her falling was like laying down. Instead, what she had to learn was to fall as if she were dropping dead: "to try and bring all the movements downwards, pulling down, down and not reaching upwards... to do the movements much larger, to fight, to push my limits, forget the steps and the dance... you had to die. [...] That's the only way it can work." The moral of the story also held true for her as a dancer: for something to get off the ground, it takes genuine falling first. The English title of the Sacre is The Rite, an apt title that captures the essence of sacrifice: to create a passage (cf. rite de passage) to another space, to another state of mind, another part of life. To allow for change at all.

Some years ago, during an exposition called Dance my PhD, dancer Mieke Koldewee let herself fall numerous times on the blue stone floor of an old church in the city of Utrecht. The rhythm of her movements was determined by another dancer, Marije Nie, who dictated strings of words and phrases from my thesis. I remember clearly how Koldewee fell repeatedly at every mention of the word 'undecidable'. This rather odd link manifested an opposite relation: the harsh reality of what happens when a decision is actually made. A person hearing that they have been diagnosed with Parkinson's must also feel the stone-cold certainty of irreversibility.

What would happen if, figuratively speaking, a person living with Parkinson's lets themselves fall down? What would it mean to embrace shakiness? What new perspectives might they find?

Pina Bausch and Tanztheater Wuppertal Perfom 'The Rite of Spring' at Sadlers Wells, London, Britain - 13 Feb 2008 photo: Alastair Muir

The patient

While I was working on this chapter, I met a man living with Parkinson's, Andreas Dijkhuis. We talked, and Andres told me a story about his experiences with falling. His rehabilitation therapist Willem Oudegeest had once asked him what he would do if he could choose one thing that to be able to do again. 'Jump over a stream,' was his answer. Then in a gym, they had created an imaginary stream with a gymnastics mat, to practice his jump. It was at that moment that he realised it was not jumping he could not do but falling. His body had forgotten what falling was: he had erased the movement from his repertoire and believed he could not do it. Learning how to fall did not only mean crossing the physical barrier in front of him but breaking down the mental barrier inside of him. To know the movement of falling from within meant experiencing it. It felt like trespassing on forbidden land. He felt he could not do so uninvited. But he managed in the end. He jumped, he fell, he rolled on and he got up.

When I asked him what his experience of falling was he answered, 'Like shaking something loose.' He did not refer to the half second of floating in the air, but to a transformed perspective of his capabilities. You can do more than you think.

The professional

In the documentary Wim Wenders' made about Pina Bausch after her sudden death, one of her dancers said that with Pina, you always felt like you were more than a human[2]. Others had a similar view of Bausch as a choreographer: her dance performances were not scripted but were born out of the lively and intense contact between Pina and her dancers, out of the confrontation between the dancers' inner world and the harsh reality of the world outside. Often their stage was outside as well, on the street, in nature, where you could trip over something unexpected. Even when they were inside, Pina created obstacles for her dancers so they would come up against their deepest emotions and translate them into movements and gestures. She would then build acts or even entire performances on what came from those moments.

But if someone is afraid to fall, how can you help that person learn? The story goes that Pina Bausch hardly used any words for that. What she did was, as the story goes, tugging her dancers towards the edge of the cliff, where their deepest desires laid dormant, where they could be superseded and the personal would transcend into the universal. Pina always focused on a person's life story to learn and understand how it could be positioned within the larger story of society or mankind.

What is of vital importance is that, again and again, Pina allowed herself to be carried away in the flow of movements she and her dancers created. She did not just oversee the process: she participated in it. A striking parallel can be drawn between the methods applied by the caregivers in this book, or with the example of the man jumping the stream. Professionals, the choreographer, and the caregiver show how their work arises from personal contact: from listening to someone's life story and to what their bodies have to say, and how the two voices may come together. How this is a dynamic process that takes letting go, allowing one's self to be touched or carried away. One of the people in the book said, "you are dancing together, metaphorically but sometimes even literally. If you manage to create a singular movement together, you enter a rhythm and you are able to achieve many things."

Changing

In my work as a consultant philosopher, I distinguish between that which is difficult, that which is complicated, and that which is complex. Quitting smoking is difficult, even though in itself, not doing something is as simple as can be. Something may also be an complicated issue, meaning that a level of sophistication may help solve it, like finding a bug in a system. Complexity, on the other hand, yields to linear reasoning, like the Covid pandemic, where new factors arose constantly, and different perspectives could not be reconciled.

Falling touches on all three levels: you have to let go of something (difficult), you have to master a certain technique (complicated), you cannot know what will happen (complex). It is in this entanglement that you can be lifted above yourself. And then, perhaps, something will change.

Sources
1 Le sacre du printemps igor stravinsky chorégraphie pina bausch & dossier: L'Arche Éditeur / Pina Bausch Foundation, 2012.

2 Pina. Een film van Wim Wenders, Cinéart, 2012.

Siebolt

& Roos

Siebolt is an artist and has had Parkinson's since 2006

Although it was diagnosed much later.

Roos is a social worker who assists Siebolt in his day-to-day life.

Roos: Back then I thought, ‘Oh, working with Siebolt will be a piece of cake.’ Of course, it’s not, because not everyone is Siebolt and Siebolt is not everyone!

Siebolt: I don’t know if you’ve heard that saying: ‘Borders don’t separate but connect.’ You have a professional level and a personal level. However, there is a very clear boundary there, and if you create distance as a client and as a professional, you are not making full use of all the potential that’s there.

Roos: When I close this little box, the contents just stay inside. Just like with me, everything stays inside.

Roos: Siebolt makes the decisions: he is the director. It’s his life, and he is in full control. There are some aspects that need attention. Because of what he is hindered by, either consciously or unconsciously, it is up to the caregiver to monitor his boundaries so he stays safe, no matter where he goes. So, knowing when to meander along, hold on tightly, and let go.

Roos: Yes, we have fun together. We figure things out together, and we do things together.

Siebolt: I have gone through a lot of different phases in my life. My first job was as a goldsmith. I had a business in Brussels. In the beginning, I made jewellery. Later, I had a foundry, and I actually started making sculptures. Those sculptures all had one thing in common: they were semi-abstract. I mean, there was no head. They weren't right in terms of dimensions, but they were people. They were humanoid figures with action and a direction; they also had a feeling, a motivation behind the chosen designs.

Roos: Siebolt needed a bit of guidance: household support mainly came down to planning things. It was difficult for him. I started working with him at a certain point, but because of his Parkinson's, it's very difficult to dare to trust him. But we actually had a good click as people right away.

Siebolt: She provides care, but that doesn't mean she knows everything. We have to assume that we learn from each other. I think that is a basic attitude. You do learn in a field like this.

Siebolt: Someone who feels heard will complain less. I see it around me; I see it in hospitals. Over the years, I have seen all kinds of shit. It all depends on the patient's experience.

Reimagining healthcare: using a new integrated and proactive approach to Parkinson's disease as a model

Bas Bloem, Marten Munneke

Background

It is becoming increasingly clear that our current approach to healthcare is not sustainable. As our global population ages, more and more people will develop chronic medical conditions. At the same time, there are fewer and fewer young people available to look after this growing population of chronically ill individuals. This problem is compounded by the fact that the young working force does not perceive healthcare as a very attractive working environment, partially because of the ever-increasing administrative load. At the same time, we are witnessing significant medical progress – think of improved diagnostic procedures and new medications. However, these innovations are often associated with mounting costs, thus contributing further to the already enormous economic burden that healthcare imposes on our society.

Challenges in current healthcare

The solution is not to simply work harder. We need to reimagine healthcare and develop alternatives for the current mainstay approaches that contain multiple imperfections. Some of these are summarised in Table 1.

Fragmentation of care:

- Poor interdisciplinary collaboration and disconnected monodisciplinary therapies
- Numerous barriers between different healthcare settings (community, regional hospitals and specialised clinics)
- Difficult, delayed and greatly variable access to services and therapies
- Traditional hierarchical approach, leaving affected individuals in a highly reliant position

Reactive approach:

- Focusing on repairing problems after they have arisen

Inability to manage complex problems:

- Lack of disease-specific expertise among many clinicians

Predominantly physician-driven care:

- Primary focus on medical management (pharmacotherapy, neurosurgery), with less attention to non-pharmacological interventions, and even less to lifestyle or social issues
- Lack of patient involvement in decision making

Emphasis on institutionalized care:

- Outpatient visits inadequate reflection of problems in daily living
- Inpatient visits often associated with poor services and outcomes

Disease-centred care:

- One-size-fits-all approach
- Emphasis on protocols that are informed by averaged group results from trials.

Table 1. *Several important barriers in today's healthcare.[1] These are visible even in high-income countries, such as the U.S. and the United Kingdom, and conditions are even worse in lower income countries.[2, 3] The inadequacies of care exist worldwide despite different models of healthcare and differences in funding. Together, these shortcomings lead to avoidable disabilities and unnecessarily high costs.*

Box: Parkinson's disease as a model condition for shaping healthcare

In this chapter, we highlight several components of an improved, integrated, and proactive approach to healthcare, using Parkinson's disease as a 'model condition' for a wide range of other chronic disorders, both in the field of neurology and beyond. Parkinson's disease is the fastest-growing neurological condition in the world; this growth is explained in part by the ageing of our population, but it is also in part due to the presence of toxic chemicals in our environment, including pesticides, trichloroethylene, and air pollution.[4] Parkinson's is a very complex and debilitating neurodegenerative condition; it is invariably progressive, but it typically has a long disease course that can last several decades. The disease features a wide range of symptoms, but it has a highly variable presentation and highly variable rates of progression between different individuals.[5] The complexity of the condition is reflected by the fact that around thirty different professional disciplines can potentially offer meaningful support to affected individuals. Optimal management consists of four components: pharmacotherapy; brain surgery; multiple nonpharmacological interventions, and self-management by affected individuals and their families or friends.

Possible solutions

The barriers identified in Table 1 offer a template for a focused discussion around possible solutions. Some of these are listed in Table 2, alongside concrete examples that have actually been tested and show promise for improving care for people with Parkinson's disease. It is worth noting that the COVID-19 pandemic, in many ways, acted as a catalyst to facilitate the introduction of some of these recommended solutions.[6] Motivated by the need to mitigate the risk of infection, people with Parkinson's disease were forced to stay largely at home, while the medical professionals that were normally involved in their care were often deployed to intensive care units. The associated lack of physical activity and the chronic perception of stress have led to a worsening of Parkinson's symptoms in many individuals.[7] However, we have also seen the arrival of creative new solutions using telemedicine solutions, such as using videoconferencing to support people at home and even to deliver interventions, such as dance classes, remotely.[8]]

Table 2. *Several suggested solutions to improve the management of individuals with chronic neurological conditions. Specific examples derived from the field of Parkinson's disease are listed in the right column.*

Possible solutions	**Specific examples from the field of Parkinson's disease**
1. To organize care close to home	• Remote/ambulatory monitoring[9-12] • Online communication[13, 14] • Virtual[14] or physical[15, 16] home visits
2. To inform affected individuals and carers, and support self-management	• Focus on the ability to adapt and self-manage[17] • Promoting healthy lifestyle, including exercise[18, 19] and healthy diet[20] • Support for working capacity[21] • Shared decision making,[22] including use of patient-reported outcome measures[23] • Caregiver support[24] • Organising peer-to-peer networking
3. To provide personalized "precision" medicine	• Readily available measures: - Focus on individual priorities of affected individuals[25] - Include gender,[26, 27] racial[28-31] or cultural differences[3, 32] • Big data and artificial intelligence: - Enable personalized profiling and individualized prognostic or treatment advice[33-35]
4. To enable access to appropriate care	• Parkinson-specific specialisation for all professional disciplines involved in Parkinson care, according to evidence-based guidelines: - Commonly engaged disciplines, such allied health professionals or specialised nurses[36-41] - Training of less commonly recognised disciplines such as dentist or pulmonologist[42] - Include nursing home staff and clinicians involved in advanced care planning (issues at the end-of-life, palliative care)[43, 44] • Concentration of care among trained experts (increase case load)[37] • Organising peer-to-peer networking[39]
5. To manage care proactively	• Timely identification of specific complications that – if left untreated – may lead to greater handicap and costly admissions; examples include active screening for precipitants of hospital admission such as near-falls
6. To deliver integrated care and continuity of care	• Breach silos by connecting all layers of healthcare and bundle into model of integrated network care, both across professional disciplines and across all echelons[45]

A new model of integrated and proactive care

We are currently introducing and evaluating a new model of integrated and proactive care in the southeast part of the Netherlands.[1] The model is depicted schematically in Figure 1; the various active components are discussed in the accompanying legend. The essence is a seamless integration of services across a highly specialised and university-based medical centre (a 'hub'), which is connected via one or more 'spokes' to regional hospitals and community-based services, allowing for healthcare delivery close to a person's home. The proactive component of this approach is ascertained by remote monitoring at home, which should ideally create an overview of relevant information for Parkinson's nurses, who can then proactively intervene if any alarm signals are detected. One example of how this system could work would be a previously stable person falling more, a progressive decline in physical activities or pharmacotherapy having a diminished effect. The Parkinson's nurse, acting as a first point of contact, could then intervene, either by solving the problem directly or by referring the affected individual to the relevant professionals in the regional medical team. Being able to have easy access to a first point of contact was identified as a key priority by individuals living with Parkinson's disease in the Netherlands.[25]

This new 'home-hub-and-spoke' model will be introduced in a partnership between one large, specialised institution (the Radboud University medical center), four neighbouring community hospitals, and the community-based ParkinsonNet network, which jointly serve a population of around 3,000 individuals affected by Parkinson's disease. Within the region, we want to bring healthcare professionals and affected individuals together and create a learning environment to help both groups learn from each other and develop skills and knowledge. The ParkinsonNet approach has been described previously in multiple publications (for reviews, see [37, 46, 47]. The essence is a nationwide and predominantly community-based network of allied health professionals who are trained according to the latest evidence-based guidelines, followed by dedicated referral to the specialised professionals so that their caseload increases steadily, thereby contributing to a further enhancement of their Parkinson-specific expertise. An additional component of ParkinsonNet is the education of affected individuals, which is delivered in close collaboration with the Dutch Parkinson's Patient Association (Parkinson Vereniging). The various building blocks of ParkinsonNet were recently summarised.[47] Taken together, this approach leads to better, more efficient care, better outcomes for affected individuals, and a considerable cost reduction, totalling around 5% of the chronic annual expenditure on Parkinson's care in the Netherlands. Because of this strong evidence-based foundation, various countries have now also successfully introduced elements of the Dutch ParkinsonNet approach. These countries include the United States (in partnership with Kaiser Permanente), Norway, Luxembourg, and Germany. While encouraging, the ParkinsonNet approach is still incomplete because the community-based allied health network is not well connected to hospital care yet, neither in the regional hospitals nor in the university-based centre of expertise. This barrier will be resolved in the new integrated home-hub-and-spoke approach.

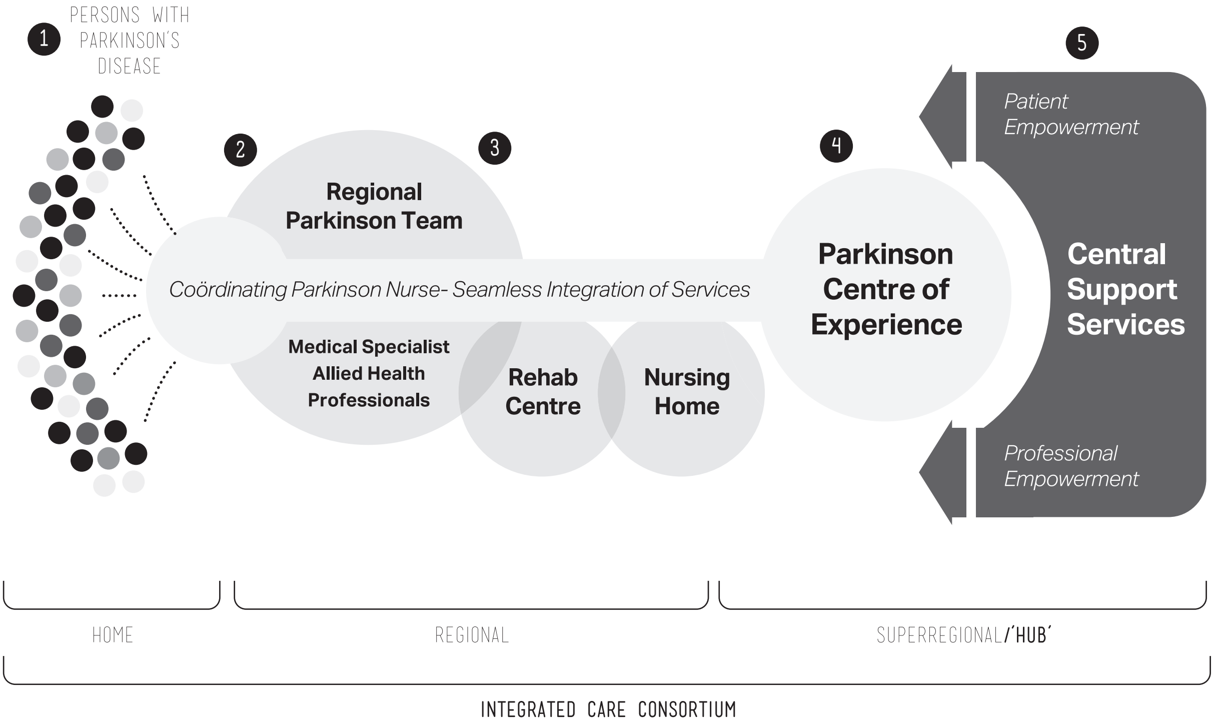

Figure 1. *The 'home-hub-and-spoke' model (modified from reference [1]). Illustration of how a centre of expertise (the 'hub' – services shown in blue) can be coupled to a single spoke (services shown in red), consisting of a neighbouring community hospital (where regional care is delivered by Parkinson's specialist doctors), a Parkinson's nurse (acting as personal care manager) and regional community-based professionals. Specific services offered include, from left to right in the figure: (1) remote home-based monitoring (e.g. using digital diaries and wearable sensors) and self-management by affected individuals; (2) personalised care management, ascertained in part by appointing extra nursing staff who can act as the first point of contact for affected individuals and families; (3) a specialised regional care team, including hospital staff of the regional hospital, allied health professionals who participate in ParkinsonNet, facilities for inpatient and outpatient rehabilitation, and nursing homes with trained staff; (4) remote peer-to-peer support offered by a centre of expertise, with the option to physically see affected individuals with specific health issues (complex or expensive diagnostic issues; device-aided therapies); and (5) centralised educational and supportive resources for both affected individuals and professionals (services shown in green). One centre of expertise can potentially support many surrounding community hospitals, thus creating multiple spokes).*

New roles for affected individuals and medical professionals

In such an integrated and proactive model of care, it is essential that both affected individuals and medical professionals assume new roles that facilitate participatory care. This term reflects a situation where both parties contribute to better outcomes, each with a difference in background (e.g. professionals have medical expertise, but affected individuals know their own situation and priorities best), but on a fully equal basis. In a TEDx lecture, we described this process for professionals as a transition from being a 'God' who – with all the best intentions – aims to look after affected individuals, to being a 'guide' who supports individuals in making the best possible decisions in a process of shared decision-making (TEDxMaastricht - Bas Bloem – 'From God to Guide' – YouTube). At the same time, we emphasised that the introduction of these participatory care concepts will benefit from eliminating the term 'patient', and replacing it with 'person' or 'individual',[48] as we have attempted to do in this chapter.

Seeing the tremendous potential of participatory care, the authors of this chapter were delighted to see the unique artistic process portrayed in this book, where discussions between medical professionals and affected individuals were facilitated by having a personal conversation about unique individual objects. One of us (BRB) participated in this process, and found it to be a highly gratifying process, allowing him to gain unprecedented new insights into the personal life of an individual who had been under his care for quite some time. The use of photography to document this unique interaction between two completely complementary yet fully equal partners is also instrumental, as it helps to convey this important message to a much wider audience. We sincerely hope that this unique project will help to further accelerate the introduction of participatory care for people living with a chronic medical condition across the world.

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Holding still, together
Portraying Parkinson’s care

This book provides unique insights into how health professionals and people with Parkinson’s disease shape care together. It shows both the courage and vulnerabilities of those who have to face this disease. It consists of photos of people with Parkinson’s disease and their care professionals, both of their interaction and portrayed individually, interwoven with fragments of their dialogue about meaningful care.

This book is an integral part of a research project at Radboud university medical center into person-centred care. With it, we hope to contribute to a positive, hopeful vision of ever-improving Parkinson’s care.

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