VULNERABLE RESPONSIBILITY SMALL VICES FOR CAREGIVERS

Linus Vanlaere Roger Burggraeve Laetus O.K. Lategan

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Vulnerable Responsibility – Small vices for caregivers

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INTRODUCTION ANTHEM FOR 'LOST SOULS'

Many books have been written on the subject of good care and ethics. The crop of books already available on the market is sufficient to fill a substantial library. Almost every book contains a wealth of inspiring and valuable ideas. So why yet another book? Hasn't everything already been said about good care and ethics? Shouldn't we rather concentrate on putting all these great ideas into practice?

Our 'egg of Columbus' is to be found precisely in this last question. As care ethicists, we cannot rid ourselves of the impression that today, more than ever, an ideal image of care is being cultivated. This is the image of the "humanly desirable", to adopt Paul Ricoeur's expression. This image might, of course, inspire and appeal to caregivers to do their best. The ideal picture of good care, as it is presented in the vision and mission statements of care organisations, poses the challenge to keep care relevant. This image stimulates the continued search to determine how the welfare of the other can best be served, in the same way that a dream incites and stimulates.

However, this ideal image can also place too much of a burden on the shoulders of caregivers. The pressure this ideal image puts on caregivers may be so great that, while it inspires and appeals to them, it also discourages them. This risk is certainly present when insufficient attention is paid to offering support to the caregivers themselves to deal with the obstacles they encounter, and which might prevent them from putting the ideal image into practice. In this sense, care does seem to be a madcap job.

A continual confrontation by one's own limitations results in feelings of powerlessness and anger, and may lead to burn-out or depression. Research on the well-being of caregivers in geriatric care, for example, has shown that emotional exhaustion is a central issue. Research conducted on caregivers who

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have taken it upon themselves to care for a family member, for instance, also indicates that many are close to emotional exhaustion.

Any person trapped in a situation where too much is expected of him/her runs a high risk of discouragement and even burn-out, or at the very least of becoming indifferent or disengaged. The original longing of caregivers to offer good care is still present, but it may have become stifled. They give care in a distant and uninvolved way. This detached, business-like care is in effect a kind of strategy for survival. For the caregiver, however, it is no less exhausting, and the care-receivers may also suffer as a result.

A kind of 'attainable' ethics could be what is needed, that can take vulnerability into account in order to avoid the collapse of caregivers as a result of their responsibilities – or even their attempting to flee from them. This means first of all, that human imperfection must be taken into account. While pursuing the care ideal, in everyday life caregivers come up against limitations, not least against the limitations from within. In addition to the external limitations, such as the context of insufficient time, or policy that stipulates other priorities, there are also the personal limitations of the caregiver him-/herself, namely in the areas in which he/she possesses imperfect knowledge or skills, depending on the individual personality and character. Ethics are also precisely related to this story of finiteness in the quest for 'good-enough' caring. This is a question – to appeal once again to the popular expression of Ricoeur – of pursuing what is "the most humanly possible" in a world that is characterised by what is imperfect.

But there is more. In addition to the limitations that make caregivers vulnerable and which they can only deal with in a matter-of-fact sort of way, they are also vulnerable from an ethical perspective. They are in fact not only imperfect, but also fallible. By fallible we mean that they can and do make mistakes: they fail and make mistakes and they do not always have the best intentions. Caregivers are not superheroes continually seeking to do good without the slightest hint of impatience or harshness or cowardliness. What parent has never been alarmed by his/her own behaviour when he/she reacts sharply to his/her child? Caregivers are human too: they are imperfect beings, often having to face their own limitations and those of the context in which they work. They are fallible: that is to say, they are not always virtuous and caring, not always the model of goodwill and commitment. Strange as it may sound, this is the adage of this book: fortunately, caregivers are fallible!

This is the reason for the choice of a kind of 'slow' ethics; ethics that refuse to lay claim to perfectionism in caregivers, in the name of a "continually improving – exacting – caring". Caregivers are not moral superheroes, completely good, honest, well-balanced, etc. Perhaps they are even better

caregivers as 'anti-heroes', not always on the ball, sometimes clumsy, vain, jealous, stubborn, absent-minded, short-tempered, and so forth. They are the image of the ordinary – and thus fallible and imperfect, just as the care-seekers are. In spite of – or thanks to? – their shortcomings, they are nevertheless still sensitive to the imperfections and suffering of others. At the end of the day, it is often exactly these anti-heroes who allow their hearts to speak. It is precisely for this reason that we are convinced that ethics also need to take the ethical vulnerability of the caregivers into account. This means: take into account a number of vices that are very human. There are, in particular, vices of which it is said that there is absolutely no place for them in caregiving. Think for example of a vice such as laziness. Or antipathy. Or anger. Displays of such qualities may seem to be inconsistent with good caring. Yet these are human, all too human, qualities. If ethics can only give the message "that is not allowed!" (and that is the end of the matter) then these qualities don't disappear but go as it were underground, and they make up a sort of insidious poison. In this book, we seek to acknowledge that caregivers can and do experience troublesome emotions, and do have negative qualities, but that we need to stop suppressing them. It's okay for them to be there. Only when their right to existence has been identified can a basis be established to tackle them.

What's more, we have the crazy conviction that some of these vices can actually have a positive effect in caregiving. From vices or troublesome feelings such as antipathy (Chapter 1), laziness (Chapter 2), mediocrity (Chapter 3), hypocrisy or doing-as-if (Chapter 4), anger (Chapter 5) and disobedience (Chapter 6). Some virtues or virtuous aspects come to light that actually make good care possible. We may speak of a paradox: small vices as a lever for virtuous caring!

The vices explored in this book make a 'perfect imperfect whole'. The chapters may be read independently and in random order, depending on the interest of the reader. They each hold up a part of a mirror. All the chapters together do not give us a complete (mirror) image. That is what is characteristic of ethics that are not heroic: it always falls short. It does not offer a clean-cut and complete argumentation. To put it in Rik Torf's (former Rector, KU Leuven) words: "It is not a blueprint for a high-minded life and does not offer seven quidelines for a perfect human existence."

Only six vices are discussed in this book, not seven – a consciously chosen incomplete number. This this is intended as an incomplete initiative to allow care ethics to find their own departure point in the human vulnerability of the caregivers, namely from both their unavoidable imperfection and their ethical fallibility. In speaking of caregivers, we mean everyone who is moved to care, voluntarily or involuntarily, professional caregiver or 'accidental' carer. We would like to inject a small and mischievous antidote into responsibility and caring, so that this caring will be good care and yet remain liveable and do-able.

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Imperfection and fallibility cannot exist without humour. Humour puts things into perspective and makes it possible to live with what is imperfect, in ourselves and around us. It also gives us a smidgen of hope in dealing with our own fallibility. Caring is as a whole good-enough caring, which allows us to penetrate to the heart of every worthwhile caring. This is why we can do no less in the final chapter than lay bare our ethical soul, namely how everything that is dealt with in the discussion of the six vices for caregivers is an expression of our own care-ethical perspective on caring. The fragility of the care-seeker elicits from us a sort of vulnerable responsibility that is the heart of worthwhile caring as a relational happening. The final chapter is also conceived as an extra chapter, a philosophical postscript that does not add anything more to the foregoing chapters, but does reveal their inspiration and incitement, embedded in and inspired by Emmanuel Levinas' thinking on responsibility.

So this book is about caring for care-givers, specifically focused on the social sciences part of being a health professional.

This book is also about us. We wrote about what we saw when we had the courage to look in the mirror, in the hope that readers will also recognise themselves in it. We hope we are reflecting on an everyday reality in making our less appealing traits visible to all and sundry. People may be sceptical about our reflections on care. They may even find it laughable. But should this be the case, we take comfort in Leonard Cohen's 'Anthem', in which he sings: "There is a crack in everything – that's how the light gets in."

Linus Vanlaere Roger Burggraeve Laetus O.K. Lategan



CHAPTER 1 WHAT DO I CARE ABOUT THE OTHER?

ANTIPATHY AS LEVERAGE FOR GOOD CARE

In the novel Summer House with Swimming Pool (Zomerhuis met zwembad), Herman Koch introduces a doctor with a rather troublesome problem: the doctor feels revulsion for the human body with all the defects big or small, that may accompany it.

I had always done my work well in spite of my aversion for the human body. I seldom received complaints. I referred the worst cases to another doctor at an early stage. I provided the less severe cases with the right prescription. It was a different kettle of fish with the overwhelming majority: those who did not have a problem. Before the summer holidays began, I listened with patience. I put on my most sympathetic face for a whole twenty minutes. But now, twenty minutes was too much.

- Koch 2012:300 (authors' translation)

Something happens in the doctor's personal life during the summer holidays. It becomes impossible for him after this event to disguise his dislike for the human body. After five minutes or so with the patients who believe themselves to be ill, cracks begin to appear in his sympathetic countenance. He has difficulty putting himself in the shoes of those patients who think they are ill, but who are not. More and more patients leave his practice ...

Antipathy in the care sector

Antipathy is aroused in care relationships because of personality differences or because of differences of attitude or behaviour: it is a reaction of one person to another. It is not necessarily a matter of one-way traffic from the carer to the client. The client may experience similar feelings towards the carer. In the doctor-patient relationship, for example, antipathy may not be limited to the one or the other: it could come from either side. Apart from the carer and patient, the healthcare management system and the environment (as community) of the carer and the patient can evoke similar experiences. Antipathy would seem to be an obstacle to doing one's job well – being a *good* caregiver, for instance. Warmth and a charitable spirit, compassion, sympathy: these are all attributes that are compatible with ethical solicitude and concern, not only for the caregiver but also for the patient, the healthcare system and the healthcare environment.

But antipathy? No, that is unacceptable. The spontaneous question is: how can we do away with antipathy?

A first approach would be to understand the roots of antipathy. The carer may like the person or want to care for the other person, yet be resistant to the idea of touching another human being. The resistance may be of a physical nature

or may be influenced by one's cultural view. For example, the carer may not like to treat open wounds. Or the carer may have cultural or gender prejudice. Should we assume unconditionally that being a carer always means that one is comfortable working with and/or touching other people?

Ruissen and Van Tilburg (2011) observe that the theme of antipathy in the care process has not yet received the attention it deserves. It seems that the literature on empathy, sympathy or even erotic attraction is more complete than the literature on antipathy. Ruissen and Van Tilburg claim that caregivers discuss among themselves those recipients of care for whom they feel antipathy. However, a frank discussion about the effects of antipathy on their caregiving and how they deal with this antipathy is evidently often very difficult and hence avoided.

Nevertheless, one should consider that antipathy may well have an advantage. To start with, there are questions that should be asked: does a feeling such as antipathy always present an obstacle to good care? How does it influence the quality of service? Are there any lessons to be learned from antipathy in care?

A spontaneous feeling of revulsion

The above mentioned novel, Summer House with Swimming Pool, illustrates that antipathy certainly exists amongst caregivers, and that it can pose problems for good care. The doctor in this novel feels antipathy towards those patients who imagine themselves to be very ill. He sees in such people an inability and self-deception or even fierce obstinacy to face up to their own reality. And of course it is precisely these individuals who want to be examined. They refuse to accept his diagnosis, even though he has many years of experience on which to base this. To examine the bodies of these people, to probe between the folds of skin and scrutinise the regions where the sun never shines: this simply revolts him. This is also his response towards patients who seldom wash themselves. Even on vacation, when the doctor catches a whiff of a sick animal, the odour of unwashed bodies assails him.

It was an odour he sometimes smelled in his surgery. With patients who let nature take its course, as they called it. Patients who refused to have their body hair removed from the places where no body hair should be; who preferred to wash themselves with water from a well or a ditch, and who 'on principle' used no chemical or cosmetic product for their personal hygiene. If one could speak of hygiene. The smell of stagnant water wafted from all their orifices and pores. Water mingled with soil and dead leaves in a blocked drain. The odour worsened when they undressed. It was as if you had lifted the lid of a pan; a pan left forgotten at the back of the fridge. I am a doctor. I have taken an oath. I treat every individual indiscriminately. But there is

nothing that so arouses my anger and aversion as the environmentally-friendly stench of the so-called nature-people.

- Koch 2012:97 (authors' translation)

The antipathy that the doctor felt for such people was very probably related to his own experience (as a doctor) and to his perception of what 'being ill' means. The aversion and revulsion he felt toward the unwashed bodies and toward people with a strong body odour probably also had a negative effect on his emotional response. Whatever the case may be, the patients toward whom the doctor experiences aversion have not consciously done anything to annoy him as a person or with the intention of hurting him as an individual.

Antipathy is always a spontaneous and irrational aversion to someone who behaves in a manner contrary to one's own expectation of a person and/or a situation. This expectation is very often subjective and biased. The antipathy increases when one expects a given behaviour and this is ignored or absent. This is especially the case when one's reasoning is that "the other person should know better" or even worse "the person knows what the expected behaviour is". Although these feelings of antipathy can be explained rationally, there is no logical justification for them. The aversion can be related to the physical appearance of the other or his/her typical way of responding or reacting. It may be intensified by the other's odour, their way of speaking, the way in which they are clothed, their behaviour such as picking their nose or scratching their head. Feelings of antipathy do not in any way have to do with an aversion for the other because a person does something or says something that oversteps a certain moral boundary. It is a matter simply of "I disapprove" or "I dislike." [In the chapter on anger (Chapter 5), we will discuss the indignation that is evoked by caregivers when this occurs.]

Antipathy is the opposite of spontaneous attraction: my spontaneous reaction is that I just can't stand the other. This feeling of aversion is moreover subjective: the feelings of antipathy are elicited in me by the other in his/her *being*. A colleague may not experience such feelings toward the same patient and may be quite neutral to the patient. Yet another colleague may even feel sympathy.

A characteristic of feelings of antipathy is that these always say more about the feelings of the person who experiences antipathy than about the person for whom antipathy is felt. We have to look for the cause of antipathy primarily in our emotional life, which is to a great extent subconscious. Why do you feel what you feel? There is not always an immediately available, reasonable explanation for this. In psychoanalysis, this phenomenon is referred to as counter transference in order to denote antipathy. What is meant by counter-transference is the feeling that the care-seeker evokes in you. This person

evokes for example feelings of antipathy in you because he/she resembles someone from your past in relation to whom you had a negative experience. What is characteristic for transference and counter-transference is that careseekers and caregivers subconsciously transfer feelings and behaviour from similar situations in the past to the present care relationship. Often these are relationships with people in your personal environment, such as family members, who unconsciously played a role in how we feel about and behave toward the other.

Ruissen and Van Tilburg (2011) are of the opinion that feelings of antipathy can also arise because caregivers, through their contact with the other, experience continual confrontation with their own actual failures, which they can no longer tolerate. Or the care-seeker has a number of traits you have yourself, but which you have repressed because you feel they are absolutely not nice or attractive or appropriate. In this case antipathy is the result of what you would feel if the other were to hold up a kind of mirror to you.

Possibly, the doctor's aversion to people who believe themselves to be ill when they are not, has to do with either the doctor's powerlessness as he/she cannot do anything for them in this situation, or with the belief that such patients are misusing illness to attract attention or to gain something from the system. Typical examples will be students who are claiming to be ill just to get a sick note not to write an exam, or a person who wants to be declared medically unfit in order to go on early retirement. In addition, the conscientious doctor may feel that the healthcare system is being exploited. Such behaviour not only gives the medical profession a bad name but also results in the increase in health insurance payments and the general cost of cure and care. Ruissen and Van Tilburg (2011) suggest that people who are not ill, hypochondriacs or who express their psychological problems through physical symptoms, patients who are demanding, in the same way as those who avoid care, often put a lot of pressure on a doctor's sympathies and for this reason evoke feelings of antipathy. In the case of the doctor in the novel, these feelings of aversion are reinforced by his physical repulsion for unwashed bodies, and because it is of course precisely these people that he has to examine physically while knowing all the time that the examination will not be productive.

Are feelings of antipathy always reprehensible?

Caregivers are human too. Feeling antipathy for some care-seekers is quite normal. Feelings are in and of themselves not wrong. Of course problems can occur when feelings of antipathy are responded to in a wrong way. Imagine for example that a doctor makes a careless diagnosis and prescribes a wrong treatment as a result of his/her feelings of antipathy (and he/she wants to be

done quickly). In such a case there is a problem. This is what happens to the doctor in the novel: he is no longer able to channel the feelings of antipathy that he had previously felt toward a certain kind of patient with an acceptable and professional attitude.

Previously, I allowed the patients (who had nothing wrong with them) to talk for the full twenty minutes. After that they went home relieved. The doctor had written out a prescription for them and urged them to take it easy. 'Make an appointment with my assistant for a follow-up visit before you go,' I said. Then we'll see in three weeks' time if there is any visible improvement. I could no longer summon the energy for this. I lost my temper. 'There is nothing wrong with you,' I said to a patient who came complaining of dizziness for the third time in a row. 'Absolutely nothing! You can thank your lucky stars that you're so healthy.' 'But doctor, if I get up suddenly from a chair...' 'Were you listening? Evidently not! Otherwise you would have heard me say that there is nothing the matter with you. Nothing! Do me a favour and go home'.

- Koch 2012:301 (authors' translation)

Formerly the doctor in the novel had still chosen to examine the patients for whom he felt antipathy. Now this was too much for him. Antipathy clearly has a dysfunctional effect here. The patient may be suffering from a severe illness, but as a result of his antipathetic feelings, the doctor is no longer able to ascertain this

It is not the feelings of antipathy in themselves, but the denial of them that can then lead to problems. Ruissen and Van Tilburg give a similar example to that of the doctor in *Summer House with Swimming Pool*. They observe:

A doctor who finds his cardiac patient irritating, because this person does not look after himself sufficiently and smells as a result, rushes through the consultation and overlooks the alarm signals. In retrospect, he realises that he even forgot to take the person's blood pressure.

- Ruissen & Van Tilburg 2011:4

Antipathy can play a pernicious role in care situations. In the examples of antipathy in the relationships between doctor and patient, the feelings of antipathy cause the doctors to forget their responsibility. They no longer manage to act professionally. Even in less severe cases where antipathy gains the upper hand with caregivers, this impedes the care relationship because it prevents an open and respectful contact with care-receivers. If this contact is absent, the latter will withhold important information: they will not allow themselves to be

seen as they really are. As a result, the caregiver is also hindered from providing good-enough care.

Antipathy is in the first place a feeling. Feelings are not in themselves morally reprehensible. Everything depends on what caregivers do when confronted with antipathy. Choices have to be made continually. If caregivers feel antipathy for certain care-seekers, then they are not instantly and emotionally on the same wavelength as these people. Their ear is not ready to listen. If they are aware of their aversion, then they can still make a choice: how am I going to deal with this antipathy? This is moreover, according to Theodore Dalrymple (2010), the sort of question we need to ask ourselves, if we do not want to end up in a sort of obtrusive sentimentalism.

Sympathy, empathy and compassion versus antipathy

What exactly needs to happen before antipathy, as a sort of 'small vice', can contribute to good-enough care without demanding the impossible from the caregiver? Before formulating an answer to this question, we need to make something clear about the role that feelings – whether positive or negative – play in the ethical involvement with, or care for, the other. We will give consideration to the positive role that sympathy, compassion and empathy play in giving good care. This may also show us something about the role of antipathy.

Sympathy: 'good vibrations' toward the other

Antipathy is the opposite of sympathy. Some caregivers possibly feel sympathy as often as they feel antipathy in their daily interactions with care-seekers. Sympathy is the spontaneous feeling of affection and appreciation of a person. Just as antipathy has to do with an emotional aversion toward someone, sympathy has to do with a spontaneous, affectionate preference for a person. This means that it involves a pure, emotional attraction. Sympathy often has its roots just as much in the counter-transference that we mentioned above, as does antipathy. We sometimes feel sympathetic toward the other because he or she reminds us greatly of someone from our past for whom we experienced affection. Or the other takes us back, subconsciously, to a situation that we found extremely pleasant.

Sympathy between two people is often reciprocal and this creates an enjoyable encounter. Without the slightest effort, we are open to the other person. Sympathy in care creates an affinity with the care-receiver. However, it is not a must. Feelings cannot be forced. Furthermore, sympathy can even

interfere with good care in some situations. The respectful, open contact that we mentioned in the context of antipathy can also be hindered when there is insufficient professional distance. We will discuss this in more detail later. Sympathy is however usually a bonus in most cases because being friendly, caring, respectful and attentive is less demanding for the caregiver.

Compassion as an active attitude of compassion

In contrast to sympathy (and antipathy), compassion has to do with more than just a feeling. Compassion is a disposition or an attitude to life that is strongly encouraged in the area of caregiving. This has to do with a form of moral sensitivity that can be acquired as an attitude. Caregivers with compassion are people who allow themselves to be touched by the suffering that others are undergoing or have undergone because they have an actively open attitude. In this sense, compassion is in the first place a sensitivity rather than a feeling. It is a sensitivity toward the suffering of others, a sustained attitude of allowing oneself to be touched. On the basis of compassion, caregivers will in this way reflect a certain justice, in as far as they allow themselves to be touched not only by the suffering of patients toward whom they feel sympathetic, but also by the suffering of people for whom they do not feel sympathy. They are even able to allow themselves to be touched by the suffering of those toward whom they feel antipathy. Furthermore, a characteristic of caregivers with compassion is that they allow themselves to be touched at all times – whether it is convenient or not.

Compassion is however more than just a moral sensitivity. A person who is compassionate not only allows himself/herself to be touched by the suffering of the other, but will also be supportive of the other person. Compassion refers in this way to a certain kind of behaviour. At the very least, people with compassion will not do to others what they do not wish to have done to themselves. If compassion is understood as pity, namely purely as a feeling or as a passive form of compassion, then it has a negative association. For example, homosexuals could always depend on the commiseration of the Roman Catholic Church, but at the same time also expect moral censure. Understood in the latter sense, namely as human feeling without ethical consequence, we can do without the other's compassion. In this case it is not an ethical stance or true compassion.

Empathy as a skill that leads to compassion

Empathy is first and foremost the conscious and developed skill of entering into the other person's feelings or putting oneself in the other person's shoes. It is through instinctively entering into the suffering of another person that caregivers know what they need to do to 'do good'. In the second place,

empathy also involves the skill of gaining insight into both what the caregiver himself feels, and what precisely the other is feeling, as well as the distinction and connection between both. Sometimes you may think that you know what the other is feeling and needing, yet couldn't be more wrong. Moreover, you can never fully feel what the other feels, and verifying this is therefore imperative. In the third place, empathy is the response that the caregiver gives, namely what this person finally does to make clear to the care-seeker: "I understand". Put briefly, empathy is a complex combination of feeling, verifying and acting that unfolds through trial and error in the course of a learning process.

Empathy as a skill is of course dependent on being sensitive to the other person's situation. Neuro-scientific research has demonstrated that this sensitivity involves the way our brains work. It is clear from this that people with no empathy at all possibly have a neuro-psychiatric problem. Much research illustrates at the same time that empathy is influenced by upbringing and that it develops through (life) experience.

Empathy is here understood as an "intelligent" emotion: it is an emotion that is nourished through upbringing, through experience, but also through art and literature. Empathy gained through the latter encourages one to enter into other perspectives.

Antipathy is not irreconcilable with empathy

So far a number of issues have become clearer. What stands out in particular is that antipathy and sympathy may well be opposites, and that compassion and empathy are not irreconcilable with antipathy. Compassion is an attitude that is unrelated to attraction or rejection. Empathy, as a skill, enables caregivers, even when they feel antipathy, to enter as far as possible into the other person's situation and gain insight from that position into what needs to be done.

The exploration of compassion and empathy in particular makes clear precisely what needs to take place to ensure that antipathy does not lead to poor care. Antipathy is purely a feeling, just as sympathy is purely a feeling. If caregivers act solely on the basis of their feelings, unconscious of the fact that these are biased and without checking their feelings against the reality and the justice that is the basis on which compassion is founded (cf. do not do to another what you do not want to have done to yourself), then both antipathy and sympathy can become obstacles to good-enough care. This means at the very least that caregivers need to be aware of what they feel toward the other, and that it is important to recognise their antipathy.

Antipathy as small vice in the care sector

Recognising one's feelings of antipathy and not disregarding these feelings is the first important step toward good-enough care. Making a choice is not possible without this step. A choice assumes freedom. Freedom is obtained at the moment that feelings are recognised and acknowledged. Additionally, this creates space: it is acceptable for such feelings to be present. Or recognising that: "I feel antipathy and this is not a problem!" Something that also creates freedom is the realisation that feelings of antipathy often say more about oneself than about the other person. When caregivers realise that they are having difficulty with certain mannerisms and actions of a care-seeker and not actually with the person in question, the feelings of antipathy have less opportunity to undermine the care relationship.

In a certain passage from the novel *Summer House with Swimming Pool*, the doctor feels clear aversion to a homosexual patient who thinks he has a sexually transmitted infection and comes knocking at the doctor's door. Under the guise of a reassuring comment, the doctor, in panic, would like to send the patient home. At the same time, he would rather not see any naked flesh or the hairy buttocks of the homosexual man today. The doctor experiences the limitations of his capacity to enter into his patient's feelings and gives the man a brush-off. The doctor is informed by his assistant that the man has left the doctor's practice in tears, saying he will never come back.

Whether it is a question of antipathy or the doctor's strong aversion prompted by his experience during the summer holidays – over which nothing more can be said without giving away the crux of the novel – is not so important. The example makes it clear that the doctor's emotions prevent him from adequately entering into his patient's reality. If he had been able to recognise and acknowledge this, he would have been able to do his patient justice, by perhaps referring him to another doctor, for example. The doctor would then at least have done justice: if his antipathy does indeed prevent him from giving good care, then it is important to limit that care to the care that he is capable or comfortable in giving. Finally, an analysis of antipathy can contribute to the quality of care for the 'future' other. If the doctor comes to realise that his own personal situation and/or past experience is the reason for his difficulty with certain patients, then it is important to face up to this honestly. Alternatively, he could make an effort to adapt to the situation, if this lies within his power.

The example illustrates how the recognition and acknowledgement of feelings that prevent caregivers from giving good-enough care – such as feelings of antipathy – can result in these no longer presenting an obstacle in the care relationship. Ruissen and Van Tilburg (2011) do point out however, that this

can have various consequences. Sometimes, if the caregiver's feelings of antipathy are insurmountable and remain present, the decision needs to be made not to enter into a care relationship. Another possible consequence is that the caregiver's feelings of antipathy are discussed with the care-receiver. This latter approach sometimes has unexpectedly positive results.

When sympathy is an obstacle to distance in proximity

The homosexual patient nevertheless returns to the doctor for another visit later on in the novel. He tells the doctor that he had gone to another doctor: a sympathetic, jovial doctor. However, precisely this sympathy rang an alarm bell for the patient. The patient recounts:

I don't know if you know what I mean, I expect so, but you have some people who will bend over backwards to make clear how tolerant they are toward homosexuals. That they think homosexuality is completely normal. But it isn't. I mean, if it was so normal, would it have taken me five years to find the courage to tell my parents? This is what annoyed me about this new doctor. Without being asked, he began at one point to talk about Gay Pride and how fantastic it was that this was possible in this city. While for me, if there is anything I find repulsive as a homosexual, then it's all those bombastic masculine bodies dancing about on a boat with only a shoestring lacing their bums. But it never occurs to some people, to some tolerant people, that you, as a homosexual, want absolutely nothing to do with it.

- Koch 2012:350 (authors' translation)

What becomes apparent from this passage is how sympathy can be just as much an obstacle to good care as making it possible. This becomes even clearer at the moment that the patient tells the doctor why he has now come back, despite the doctor's behaviour during the previous visit: he wants to be taken seriously. This is only possible when there is a certain distance between the professional caregiver and the care-seeker. If it is evident that a doctor likes you, you may call his/her professionalism into question. You are after all not looking for someone who likes you; you are looking for someone who can help you. The homosexual patient expresses how he doesn't experience his homosexuality in any way as being something nice, but rather as something that is a reality and that has demanded a process of acceptance that has not been at all nice. He expresses that one is sometimes better served by someone who gives you the space you need. He has also come back to the doctor precisely because the doctor did take him seriously. The relationship is more honest, without having to beat about the bush, without having to spare the other person. This doctor doesn't camouflage anything and consequently makes him aware of his responsibility. Pointing out a person's responsibility is a strongly underestimated form of respect that can be expressed by caregivers.

The passage from the novel makes it quite clear that sympathy at times does not introduce the necessary distance needed between caregiver and patient, to respect the otherness of the other person. Paternalistic or patronising care can be the result of too many positive feelings toward the other: the caregiver wants so much to do the utmost for the other that he/she is inclined to take over. Or caregivers are so sympathetic towards the other that, without thinking, they do what they themselves would appreciate, without reflecting that the other might not feel good about this at all.

The philosopher Emmanuel Levinas (1978) comments that sympathy in this latter sense can have the result that people recognise themselves in the other as "another I", so that they end up back with themselves without truly reaching the other. This reciprocity of sympathy can block the entrance to the secret of the other as 'unique' other. However close, the other remains a stranger, even in an intensive care relationship. Even if a sense of *togetherness grows* between the care-seeker and the caregiver, they remain opposite each other, so that they can each freely focus on the other on the basis of their otherness and can in this way acknowledge each other, in the context of a care relationship, which is always asymmetrical, both going out from myself toward the other and from the other toward me. Levinas captured this concept very well when he said that the other is not only an alter ego.

Neither 'the other' nor 'I' are terms that are interchangeable. The other is what I myself am not: the totally other, who facing me in his weakness is also the strong one with authority.

- Levinas 1978:162-164

He continues to say that there is no greater hypocrisy invented by well-organised charity than this. In the proximity of the other, the other maintains his distance, even if there is an emotional attempt to bridge it. He concluded by observing that the asymmetry and the irreducible distance never disappear in the reciprocity of the relationship (Levinas 1978).

This does not of course mean that caregivers, in the continued absence of sympathy – as is the case with antipathy – can spontaneously have respect for the otherness of the other. That respect demands that they become aware of the antipathy that they feel. They can then become aware of the fact that they may do the other an injustice if they continue to allow their feelings of antipathy to dominate. Basic courtesy and etiquette can be of assistance here. The relations remain aloof, austere and cool, but at least no harm is done to the other person.

The doctor in the novel previously succeeded in concealing his antipathy for certain patients. He submitted to the standardised game of external form and appeared to be extremely friendly and courteous toward those patients for whom he actually had no amiable feelings. Through his smile and his friendly words, he at least succeeded in treating the other with respect, in spite of his antipathy. This respect is only the beginning of good care, but it is at least a beginning.

The ethics of everyday forms of courtesy are often ignored, as is the ethical force of ordinary amiability. Ethics are almost automatically linked to a kind of framework that helps us to decide carefully what would be the best way to proceed in a certain situation. However, something precedes this that already brings us into a caring relation with the other. The way in which a doctor begins his consultation, by for example indicating his/her willingness to listen in a friendly and hospitable way: "I'm listening", creates room for the other, irrespective of whether or not the doctor is feeling sympathetic or antipathetic. The patient is given the opportunity to make an appearance independent of and preceding any preconceived notions or presentiment of the caregiver.

In the care sector, numerous issues demand the attention of caregivers. They permit themselves to be claimed by (and for) the presence of the other by refraining from immediately carrying out all sorts of care activities, and by rather truly making themselves available to listen, by physically turning to the other, for instance, and by not being preoccupied with other things such as switching on the computer or getting instruments ready. Through the "I am listening" greeting, they are already involved with the other in a caring relationship, independent of antipathy or sympathy towards the other, even independent of their willingness or unwillingness to deal with the other in a caring way.

According to Levinas, greeting a person, or saying "Good day" – a form of courtesy once again – is actually a sign of involvement with the other. Availability is expressed through the articulation of "Good day". "Good day" is not an announcement such as "Isn't the weather lovely today." It is a wish. Or rather, it is a blessing: "I wish you a good day today." Through the simple "Good day" the caregiver indicates his/her concern for the other. This concern precedes any feeling and every judgement the other may evoke in. We say "Good day" to a person even before we know that person. Just as with the address: "I am listening", the "Good day" is an expression of attention that determines all further communication.

Sensitivity to the other precedes feelings

Antipathy, therefore, can lead to (the beginnings of) respect and acknowledgement, even without much ethical reflection. The forms of communication used by caregivers to do their job are in themselves already an expression of a relationship that they have with the other, even before they have any particular intention or even a feeling toward that other. The question: "Do I have a care relationship with you?" is, from the point of view of care ethics as the care ethicist Marian Verkerk (1996) points out, a superfluous question. This care relationship already exists before the caregiver can pose the question. The caregiver is already involved with the other, and this comes to expression through saying "Good day". Even considering not greeting someone indicates that the person making this consideration is already involved with the other (whom he wants or does not want to greet).

What is emphasised here is that the ethical relationship with the other precedes all and every emotion(s). To express it paradoxically: our sensitivity to the other precedes our feelings for the other. This ethical sensitivity is not an emotion that is either present or not. It is rather: we can be touched. We are responsive, in spite of ourselves, and this extends to our physicality and emotions. We are literally touchable: we face the other and are involved with the other. This is not because we want to be so, but this is the way we are made.

This is, in other words, our human condition. Levinas speaks of our "sensibility". It is because we are sensitive that we too suffer from the other's suffering, as will be further founded in the philosophical post-scriptum (Chapter 7). This ethical vulnerability is moreover the fundament of compassion and of responsibility to care. Fortunately, we are not *untouchable* and impregnably armoured, but thanks to the incarnation of our spirit and mind, we can be vulnerable to the well-being of the other. Even when this gives us pain (or joy), we discover our human condition in our connection with the other. Levinas puts it this way:

The other is my concern before I make any decision to be concerned about the other. I am united with the other before entering into any commitment to them. Covenant, prior to every contract. We are close to each other before approaching the other, a proximity that is never close enough. This is our vulnerability, namely sensibility, the possibility of being touched, including the trembling of our body at exposure to the suffering of the other. Hesitancy, breathlessness, uneasiness, sleeplessness, suffering through the suffering of the other: ethical vulnerability as a result of our physical 'subjectivity'. Our body becomes animated through the vulnerability of the other, through which we are turned to face the outside – towards the other, even before we

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can ourselves turn to face the other – or turn away from the other. The soul of our being-with-and-for-the-other: the miracle of the infinite in the finite!

- Levinas 1974:77-113 (authors' translation)

This view is strongly connected to the African philosophy that we are human beings because of other human beings. This resonates with the broader African philosophy of Ubuntu. Ubuntu means you care for people, or in Levinas' framework: you care for the other.

Whether caregivers feel antipathy or sympathy, they are already in a relationship with their care-receivers precisely because they are already involved with each other as human beings: that is their human condition. How caregivers feel about this relationship and the effect that these feelings will have on the care relationship is a different question. We have demonstrated in any case that antipathy is not an insurmountable issue. Feelings of antipathy are normal and these feelings do not have to present an obstacle to good care. As long as they are recognised and acknowledged, such feelings can even make caregivers extra alert to the fact that they will have to make an effort out of fairness to the other person. They can even be viewed as small 'electric shocks' that help caregivers to be more focused.

Antipathy is in itself a sign that the other does not leave us cold. We feel neither antipathy nor sympathy for a complete stranger we pass on the street. The ethical relationship with that stranger is limited to a formal, friendly greeting, in which we wish him/her the best. Feelings of antipathy however demonstrate that we need to be more involved with the other than that. The other touches us and even touches us in such a way that we cannot remain unaffected, even if we would find this preferable. This is the irony of antipathy. The ethical challenge lies in making the involvement a positive and responsible involvement. And this transformation does not imply anything spectacular, only a recognition of what you are feeling. It is a conscious choice: Good day and all the best.

Care incentives

The following questions and activities can guide the caregiver in dealing with antipathy:

- 1. While reading the chapter, keep one person in mind for whom you have feelings of antipathy and one person for whom you have strong feelings of sympathy. How do these feelings come to expression?
- 2. Compassion is a skill that can be learned, trained and developed. Describe how you have seen your compassion grow.
- 3. Becoming aware of your feelings of antipathy is in the first place learning something about yourself. It is also the first step toward adjusting your attitude in the context of care. "I do care about the other." When you think about the person for whom you have feelings of antipathy, what do you learn about yourself?
- 4. How do you give expression to your antipathy?
- 5. In what sort of situation have you been impolite toward someone for whom you felt antipathy?
- 6. Give an example of a situation in which you were able to empathise with someone for whom you felt antipathy.

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CHAPTER 2

LAZINESS? WHAT LAZINESS?

CAREGIVERS ALSO HAVE A RIGHT TO BE LAZY

In his autobiographical novel, *The Old King in His Exile* (2017) (*Der alte König in seinem Exil*, 2011), Arno Geiger tells of the demanding care required by his father who was suffering from dementia. He speaks of how taking care of his father was inconvenient for every member of his family because each of them had other commitments. The demanding care for his father came just at the time when he had gained a reputation as an author and was asked to give lectures all over the country. He writes:

I was on an almost-nonstop book tour. As often as my conscience allowed, I would leave my partner and spend the weekend in Wolfurt [with my father]. I was a mess. Often I felt torn between love, family, and career. Sometimes one of them seemed burdensome, sometimes another. I was not used to such a nomadic lifestyle, nor to proper time management, and taking on responsibilities was not one of my strengths. I had always seen myself as a playful kind of guy, as someone who couldn't give up his route across the rooftops. Never mind. We always give our lives a form, and life always smashes it.

- Geiger 2017:65-66

Time management – with its goal of accomplishing as much as possible in as little time as possible – is exceptionally important in healthcare. The caregiver who manages to save time, work efficiently, and get a lot done in a short period is highly valued. There is of course a perennial shortage of caring hands – and of time. Students doing their workplace experiential training in a hospital find for example that they receive a good evaluation from caregivers if they manage to wash several patients within a short period. The opposite is however also true: the person who works more slowly is quickly identified as someone whose work is below par since it is efficiency that is important. There is after all so much to be done.

Slowness in care is not *permissible*. It is very quickly perceived as laziness. The caregiver who inadvertently stops to have a bedside chat without actually doing anything is wasting his/her time and is lazy. Is this fair? And, if it is a case of laziness, is laziness a sin in healthcare?

Time and sense of time in the care sector

You have a clock but no time. We have time but no clock – old African proverb.

To answer these questions, we will first of all consider the dimension of time and the sense of time. Since the invention of the mechanical clock in the tenth century, the time according to the watch or the clock has been a law to which we are all strongly subjected. The clock rules our whole life as a matter of

course. Time can be experienced in various ways, however. Think of a beautiful concert. The two hours that it takes may feel like only twenty minutes. Recall a disciplinary discussion with a colleague, however, and the one hour might have felt like an entire day. So there is time and the experience of time. What about a slogan such as "now is the time"? Evidently this does not refer specifically to a physical time. Koine Greek assists with this time differentiation. *Chronos* refers to physical time whilst *kairos* captures experiential time. The concept of *kairos* is well captured by Augustine, who made it clear that the experience of time has to do with the memory of the past, with what it is offering us at the present moment, and with the future which may or may not offer us something for which we can long. This is experiential time or *kairos*.

Suffering from the clock: the clash of chronos and experiential time kairos

It is not difficult to find an application of Augustine's distinction between *chronos* and *kairos* in the care sector. In the experience of many care receivers, the clock ticks much slower. As a result of illness or the deterioration accompanying illness or age, time is experienced differently than it was in the past. People who are ill often suddenly feel that they can no longer make any plans since their future has become uncertain. In their experience, all longing for the future has been erased. Becoming more or less consumed by nostalgia for the time when they were healthy makes it difficult for them to hold on to the present. The time of the clock takes them off guard, and it becomes almost impossible for them to find a fitting way to get through the day. The temptation to be discouraged lurks close by. Xavier Thévenot writes from his own experience:

You are ill because you have become ill. You literally fall ill. It is the sort of fall in which you are completely swept along. You are not sure where you are heading or how deep it will get. When it became apparent that I had Parkinson's, I thought it would be sufficient to give up certain activities or to reorganise them. The more this paralysing disorder developed, the more this turned out to be a bitter illusion. The days sometimes seem long. Very long. Too long. Boredom can make its entrance at any moment. Boredom evokes for me the image of death more than anything else. It represents a sort of deferment of time: nothing happens any more. Boredom is a hole in being. The days have been hollowed out. They are no longer accompanied by experience, or purpose, or significance. They change into a featureless desert that is filled with emptiness. This boredom encompasses me with sleeplessness, especially at night. It is like a dark infinity that persists unbearably, taking the same shape of the same time.

- Thévenot 1997:20-21, 43 (authors' translation)

To the person who is ill or dependent on care, every day resembles every other day. This is something expressed very often by elderly people and the chronically ill. There is nothing more to look forward to. Nothing significant happens any more. There is nothing else to do than kill time. Switch the television on, switch the television off. Wait. Eat. Sleep. Look for distractions. Time becomes timeless. It becomes eternal. Life becomes waiting, without looking forward longingly to something.

Thévenot speaks of how his existential suffering through time is related to a future that is characterised by an enormous uncertainty as a result of the disease. No more plans can be made, meaning that your future is denied you. It is no longer possible to write a new story. This also immediately raises questions about your past. In a future story, you perpetuate who you were in the past. Thévenot makes it clear that the experience of *chronos* has to do with longing (future) and with remembering (past). Paul van Tongeren suggests that existential suffering through time has to do with the future or the past if something goes wrong with the future and with the longing for it, or with the past and the longing to cling to it, then existentially suffering through time arises.

As an example of a form of suffering that is making its appearance more and more frequently, we refer to those elderly people of whom it is said that they are weary of life. This concerns elderly people who are no longer able to attribute meaning to their days and to *chronos*. They literally suffer from time. There does not seem to be anything more to look forward to in the future, other than death

The last tick of the clock is awaited. For such elderly people, meaning lies in their past. In contrast with what they have done with their lives, with whom they have been associated, and with the relationships that they have developed, what they are and do now seems to have lost every link with that past. The *meaning* of what they do now has vanished with this loss. The weariness in the term *weariness of life* refers especially to the experience of time as meaningless, time that refuses to pass, and the delivery of death that refuses to come.

The care-seeker's suffering from time

Sometimes suffering from time is also the result of a collision between several perceptions of time. Caregivers generally have too little time to spare: a quarter of an hour passes quickly when two patients have to be washed and they are also called away to respond to another call for assistance. The time perception of the patient is often completely different. A quarter of an hour lasts a very long time when you are waiting for your caregiver to come and wash you and are not able to begin any other activity until they do so. If you

as a caregiver briefly become a patient, this is often a contrasting experience. Suddenly the caregiver realises that the concept of time he or she has as a caregiver, such as "soon" and "immediately" is not perceived at all as "soon" and "immediately" by the care-seeker. Furthermore, those caregivers who are able to put themselves in the shoes of their patients' experience that the time spent with the caregiver – for example while bathing a bedridden patient – is much more intense from the perspective of the patient. As a patient, you look forward to the moment that care is extended, not so much for the care itself, but for the human engagement. You long for a person who will give you all of their attention – just to spend a little more time with you.

In daily activities, such as eating, sleeping, washing, a visit to the bathroom, care-seekers receiving chronic care are dependent on the schedule and the work flow of the caregivers. They are not able to choose their own pace. Sometimes this is felt to be disorienting. Suffering from time arises however especially when caregiving is insufficiently adapted to the patient's perception of time *during* its administration. Suffering from time occurs more frequently when caregivers are very task-oriented in their approach to work and carry out their care activities without taking into account how their patients feel.

Suffering from time from the caregiver's perspective

Caregivers also suffer from time. Caregivers speak for example of how they always have to hurry in the morning to get all the patients on the ward washed. They feel as though they are robots who have to do their routine work mechanically, in as little time as possible. They are usually aware that giving attention to one person involves a reduction of time for another. However, often it is not that simple.

Research indicates that time pressure is an important factor in relation to *moral distress*. Moral distress means not succeeding in implementing, adequately and to one's own satisfaction, one's own view of what good care in practice is. Moral distress arises when caregivers do know what the right thing is to do, but when restrictions in the care organisation or personal failure prevent the caregiver from acting according to this view or intuition. Research on moral distress has, up to now, identified in particular the hindrances in the organisation of care. One of the main hindrances is related to work overload on caregivers and the resulting lack of time for those matters that they themselves find really important. Canadian research on moral distress among nurses shows that nurses suffer a great deal from the fact that they only have time for what they call basic care (Varcoe, Pauly, Storch, Netwon & Makaroff, 2012). They are seldom able to give 'detailed care', even though they find this kind of care extremely important.

The Canadian researchers' reference make it clear that lack of time is sometimes a question of priorities within the care organisation. Nurses today have to spend a great deal of time gauging and quantifying care matters (known as the bureaucratisation of care). This is often at the expense of the time that could be spent caring for patients. Care provision is often thwarted by strategies intended to increase efficiency in care. Marc Desmet and Ria Grommen (2005) also write about such standards of efficiency in care provision. They refer among other things to the IT pressure that overwhelms the care sector: everything has to be digitally registered with the intention of making the care process more efficient by speeding it up. This striving for more efficiency is however often at the expense of time for the patient, and a great deal of energy is also demanded of the caregivers through the constant changes that accompany it. This is tiring, even exhausting.

Two types of laziness

Time pressure is accompanied by suffering. No longer being able to do what you feel you should do as a caregiver because too little time undermines in the long run the core of your professional identity as caregiver. Moral distress results in one feeling oneself to be not only a poor caregiver, but also a bad person. This feeling will possibly be familiar to many carers: it is the feeling of not coming up to the mark. If the care becomes too demanding, a "compassion weariness" may possibly arise, causing the care to go awry. This happens gradually and often takes place unnoticed. Some carers become unpleasant and rude or even begin to threaten and shout at their care-receivers. They no longer take the care-receiver seriously, something that leads to infantilisation and derogation, faulty medical? administration and poor hygiene care. Discovering and realising this failure in oneself in a care situation results in a very pernicious feeling as it touches the caregivers very deeply. It can frequently lead to caregivers and carers falling apart. They become psychologically weary, exhausted and depressed, or they may become indifferent and aloof. As strange as it may seem, all of these matters have something in common with laziness, one of the seven vices.

Laziness as indifference and a way of suffering from time

In her book on the brain, neuro-psychologist Margriet Sitskoorn (2011) allocates a chapter to laziness. Laziness is in her opinion a form of emotional apathy, whereby a person is not or is no longer able to empathise with the situation of the other(s). The person has become, as it were, socially unfeeling, or ethically indifferent. In the case of social laziness, this concerns in the first place indifference to the suffering of others.

What does this sort of laziness have to do with suffering from time? At the one end of the spectrum there are the people who no longer want to get out of bed or leave the house and who can literally no longer find the energy to make their way to other people. At the other end of the spectrum there are the people with an overfull diary, but with an empty or hollow life: through being so busy leading a life under time pressure, these people no longer have the energy to be concerned about all sorts of greater and smaller evils close at hand or further afield. They also no longer have the energy to respond to others.

Sitskoorn (2011) is convinced that laziness is an ethical problem: it keeps you from doing what is good, for yourself and for others. In this way she concurs with the way in which laziness is understood in the tradition of the seven cardinal sins, namely the sort of indifference or depression in terms of which a person is no longer able to do what is good and consequently find their happiness in doing it. Traditionally laziness is called one of the seven cardinal sins because it paralyses a person from doing what is good and (thus) from being happy. The person is so depressed or indifferent that he / she is no longer able to care for others. It is precisely for this reason that laziness hinders our own happiness. Caring for the other has repercussions for our own good.

Through Sitskoorn's (2011) approach we can see how laziness as ethical indifference can be the result of life (and work) under enormous time pressure. Desmet and Grommen (2005) also describe in their book how psychological tiredness or depressive exhaustion can be the result of being overburdened, or of hyperactivity. You become so exhausted as caregiver through all the running about and being in a hurry, in particular mentally, as you constantly have the sense of falling short in your use of time and in your attention for what is good, that you are in danger of becoming indifferent or depressed. In general, depression is usually characterised by a general lethargy and listlessness: you sit by the roadside staring despondently into space and allow the whole world to pass you by. You no longer join in with anything because you can't find the strength to make the effort any more. Or you become indifferent and keep yourself busy with your tasks, no longer allowing yourself to be touched by what has happened to others. We can speak here along with Sitskoorn (2011) of *laziness as ethical indifference as the result of hyperactivity*.

Laziness as future tiredness that has some grip on chronos

We can however approach laziness in another way.

Levinas does not speak of laziness as indifference. For him, laziness is, in the first place, shrinking back from making a start. It is not yet beginning with an activity and postponing it a little. Laziness is the minute between the signal

that the alarm clock gives for you to get up and the moment when your foot first meets the floor. Laziness is the minute – or the five minutes, depending on how easily you get out of bed – that you take to do as though the world and its cares do not exist. Laziness is the time you allow yourself to doze off a little longer. Or, to give another example, laziness is the very last minute of the coffee break in which you enjoy that last gulp of coffee as though a whole work-free afternoon were to follow.

Levinas says of laziness (1947/1978): it is a renunciation of the future. You do not begin with the future – you also delay the beginning of the future for a little while. Laziness is even momentarily denying that there is a future. Laziness is the "not just yet". The world is knocking at the door, but you don't as yet open the door, you only set it slightly ajar. Laziness is moreover shrinking back from the effort that will be required and for the tiredness that will accompany the effort. In this sense, laziness is an anticipated tiredness or a future tiredness. It is being carefree for a little longer.

From this perspective, laziness is a way of dealing with time pressure. Laziness is even a form of resistance to time pressure, to the effort that is required, to the 'dictatorship' of *chronos*. The slogan of the sixties and seventies arose from this: "right to laziness". Laziness is a (an ultimate) resistance to the pressure to succeed and the need for achievement. It is choosing to disregard the clock. This right to laziness is sometimes also claimed by caregivers: making time for the coffee break despite the shortage of time can be a way of saying that the demands are unacceptable. Caregivers also have the right to laziness! Even if the laziness is there to make sure that laziness as indifference is kept at bay.

This sort of laziness can of course get out of control. It is a "little vice". If is assumes an unrestrained form, then it is possibly no longer so small and no longer so constructive. At its core, laziness as a 'small vice', namely as a refusal to undertake something or setting to work, and as future tiredness, does have a positive side: it provides a practical way of dealing with time pressure. In that sense, laziness as a small vice has something virtuous about it. Laziness makes it possible to escape a little from the clock, to appropriate time to some small extent in order to align time better with our own perception of time. In many cases this means *slowing down*. Laziness as shrinking from setting to work can also be accompanied by a form of slowness that can have very positive results for all those involved in care.

Laziness as small vice in the care sector

How can caregivers deal with time in such a way that they don't give way under the time pressure? How can the pitfall of laziness as ethical indifference

or depressive exhaustion be avoided? How can laziness be introduced to our care situation as a small vice, namely as a healthy way of dealing with time pressure? How can caregivers exercise their right to laziness in practice?

Laziness as slowness

Laziness as a brief shrinking away before setting to work is appropriate when it helps us to let go of our own time and to step into the time perception of the other. This is not possible without choosing for the other, thus making an ethical choice, with possible difficult consequences.

A man begins to cry during his bed bath. He is paralysed on one side and speaks with difficulty. He talks about the war and points to a photo of his deceased daughter. "There", he says, "that's the whole problem ...". The caregiver doesn't respond and just goes on washing him.

- Coucke & Lammens 2006:70 (authors' translation)

This example makes it clear that there are two time perspectives that are radically opposed to each other, namely that of the man and that of the caregiver. Levinas (1947/1978) calls this "diachrony" because it involves two sorts of time that do not coincide, namely 'my' time and the 'other's' time. Both exist alongside each other and they even come into conflict with each other. The caregiver probably has to wash a couple of people within an acceptable period of time. Possibly he/she is running behind schedule and the residents who are still waiting for their bed bath will be disgruntled over the delay. It is not very convenient that the patient starts to cry right at this moment. This may be the reason why the caregiver chooses not to respond to the very clear signals that the patient is giving. Responding to the signals would require the caregiver to ignore his/her own time and to enter into the other's time. It is not a choice without consequences, for if the caregiver makes time now for this one person, the other residents will have to do with less time. However, the choice that the caregiver makes is not without consequences. The patient is clean after being washed, he/she is finished, but he/she may feel deserted. The caregiver may also be left with a bad feeling about this incident. The situation could have been prevented if the caregiver had just communicated to the patient: "Would it be all right if I come back later after I have helped the other residents who are waiting for me?"

Sometimes – off course not in all situations and contexts, such as situations that ask for 'emergency' – a caregiver has to lose time in order to gain meaningful time. Leo Feijen makes this clear in his book *Tijd nemen* (Taking Time) (2010) with a simple example from his own experience. He speaks of how he cycled up the Alpe d'Huez with his son, and how his son in all his youthful strength, cycled in front much faster than he. Every couple of hundred metres, his son would

stop and wait for his slow father to catch up. Feijen writes of how his son, by losing time and waiting, made something of inestimable value possible, namely that they grew closer to each other. Further on in the book, he describes a similar experience, but this time one between himself and his dying father. He describes the last week with his father in this way:

Life was reduced that week to the essentials of life. All incentives had fallen away, all stimuli had disappeared. All that mattered was that my father got a sip of tea or water at the right time. It was important to clean him up on time. It was important for him that he was shaved and could hear the music that he loved. It was important for him that his hand was held when he asked for it. It may sound paradoxical, but I have enjoyed this week because I have lived at this slow pace more attentively than ever. Slowness is an appeal to wait and stay it out, a request to not take flight and to live beyond the pain and the nakedness. [...] I waited beside my dying father, but I have never experienced life so intensely as at that time. During the wait my father opened up and shared the deepest longings that he had ever expressed to me.

- Feijen 2010:144 (authors' translation)

Feijen makes clear in this anecdote where laziness as a certain slowness and as an appeal to wait for the other brings us: closer to the other and closer to ourself. In such a context, slowness does have an influence on our own 'good'. This repercussion is however through the other: by deferring our own time perspective and by entering into the other's time, we form a bond with the other. This bond with someone other than our self is where people find meaning and significance. This is exactly the way in which Geiger (2017) also expresses how caring for his father shaped his busy life, a way he had not himself chosen, but through which he did experience that caring for his father made his own life meaningful.

Slowness as attention for the other

We read something about attentiveness in Feijen's account of his caring for his dying father. Slowness also relates to attention. Earlier in this chapter we wrote about the importance of being attentive to the perceptions of the person who is receiving care. We made it clear that being attentive has a subjective effect; it is in and through the attention that the caregiver bestows on the care-seeker that this person feels that he/she is a person and not an object. A patient in a hospital expressed it in this way after having being washed by an attentive nurse: "I feel not only clean, but also more human." This is exactly what Andries Baart describes in his beautiful work on attention:

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[...] attention, the not to be relinquished criteria for good care includes the other, ensures that he or she is involved and offers the other the space to be there and invites him or her to a life of his or her own face to face with me.

- Baart 2005:72 (authors' translation)

Or, as he summarises the heart of his message in the epilogue of his book:

Attention offers the seed of a relationship, and a person will rise from it.

- Baart 2005:162 (authors' translation)

Attention rests on watchfulness, a positive turning toward the other. In this sense, attention demands a conscious choice. It is the decision to give the time that you have to spend, right now, at this minute, to the other. It is the choice to be completely committed to this person and to this task. It is not wanting to do everything at once, but first one thing, and only then the other. It is for example the caregiver's choice to be fully present during the eleven minutes available to wash an elderly patient. Or, if you have to go a fair distance anyway from one ward to another, to then choose to use the time to chat to the patient. In this sense, giving attention does not always mean more time; sometimes it is just seeing that there is time and choosing to make use of it for the other. As a caregiver in the day clinic also remarked, in the task of having to fetch and accompany a patient, time is made available to spend on the other. Mentioning to the care-receiver that you have too little time and agreeing to come back later at a specific time to talk further is also a way of giving attention.

Sometimes attention does of course demand more time. If the caregiver in the example above were to respond to the signals of the older patient who has started to cry, then it is possible that he/she will need extra time for this person. In this case, attention demands a choice in as far as the time that you spend on this person will be at the expense of the time that you can spend on another person. In this sense, attention requires practice in order to find the balance between giving too much or too little attention.

Bestowing attention does offer the caregiver the advantage of being less burdened by time pressure. You are in the now. Bestowing attention offers another great advantage: by doing something attentively, you do not feel that you are a robot that routinely does things. The more attentively you provide care, the more human you become. Bart refers to this when he writes:

[...] attention helps us to be careful, or even better: to be prudent. Attention is then intrinsically related to the classical virtues such as "prudentia" and "discretio": knowing how to keep time. Attention interrupts the putting in order and bustling business of life. The idiomatic spanner in the works.

- Baart 2005:49 (authors' translation)

Attention decelerates not only because it leaves less room for time pressure through its different approach to time, but you have to decelerate to be attentive. Geiger's whole novel about his father with dementia testifies to this. The care for his father demanded sacrifice; the family's schedule took on a completely different turn. Geiger (2017) describes how he has to get used to his father's rhythm again when he takes responsibility for caring for him. He describes how the hours drag on and how it is through reconciling himself to this and by accepting it that he can also allow himself the time to pay attention to many things. He describes how hardly anything escapes his attention, and how he can lucidly and alertly embrace the things that take place. It is precisely in this way that he makes a connection with his father that was previously unthinkable and that just didn't exist.

Slowness as thoughtfulness

Right at the end of the novel, Geiger (2017) comes to the realisation that he only now, in the course of the slow process of caring for his father, in the course of writing his novel, understands things and has gained insights which would not have been possible without that slowness. He writes that he only now realises who he and his father have become and what has inspired them both. He means this in the first place possibly very literally. He comes to the realisation that at the onset of his illness, they have been totally mistaken in their assessment of his father and as a result have at some moments not treated him correctly. Only with the passing of time, through the slow hours of being with his father, and through the connections that were established through them, did the insights occur that made a better judgement possible. "You are very mistaken", his father had to say to him repeatedly, in his own reflective way. A feeling of solidarity with his father also grew through the insight that developed with the passing of the years. But this demanded time. "I had not yet come that far", Geiger writes, because: "I am a person who thinks slowly".

Slowness involves a slowness of thought. It is to this sort of thoughtfulness we refer as a third and final strategy to appropriate time. Thoughtfulness is a sort of midway point between taking too much or too little time to make a judgement. Thoughtfulness means: taking the time that is required to make a judgement without leaving it to be decided by time. That means: slowness is a deliberate action to be as accurate as possible. Making an ethical decision is only possible if thoughtfulness has been brought to bear on it. Thoughtfulness means that we should not make a decision too quickly, and that it is better to initially refrain from making a judgement. In this way, we give the other the time to reveal him/herself, and we ourselves can then take the time to have a good look at the other.

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Anselm Grün and Friedrich Assländer (2007) make it clear what thoughtfulness means in practice. There are many decisions that one makes intuitively. These are quick decisions. These quick decisions are sometimes useful, but not always. One needs a healthy measure of discernment to be able to see when it is appropriate to make a quick decision and when it would be better to take more time to do so. Taking time does not mean postponing. It demands courage, at times, to put off making a decision. Sometimes, even if only for the night, this is enough to allow a decision to mature. Thoughtfulness is the time that is needed to reflect on decisions.

There is an accompanying insight in thoughtfulness itself: the insight that comes with time brings wisdom. To a certain extent, this puts ethics into perspective. It brings out that slowness as an appeal to wait for the other, as an appeal for attention for the other and as thoughtfulness can sometimes help to appropriate time, but that at the same time that this is not always the case. It brings out, moreover, that ethics often involves thought as something that only crystallises later on, after something has happened. In caregiving, ethics involves an inherent slowness. Ethics often evokes an insight later on that is already outdated. At the same time the later insight prepares us possibly to do things differently next time. The slowness of ethics sometimes helps us to gain time: by taking a step backwards and putting on the brakes, we actually progress and don't race on in an empty and meaningless succession of activities and tasks. This is the wisdom of, or in, slowness.

Care incentives

The following questions and activities can guide the caregiver in dealing with laziness:

- 1. In what sort of situation do you put on the brakes? What effect does this have?
- 2. Can you think of everyday moments in your daily routine that you could spend differently so that you would feel that you had more time for the other?
- 3. Think about a situation in which you were able to bring time to a standstill. When have you been able to do this? What did you need to do so? Did this happen in response to the call of the other or on your own initiative?
- 4. Are you familiar with an *attitude* of slowing down/becoming unhurried in your work? In other words, is it possible (every now and then) to postpone a technical task because you sense that the patient or his/her family has need of a listening ear?
- 5. Slowness is another way of mastering time, of dealing consciously with work pressure and priorities. Do you give your colleagues the room to be different in this respect? Is this slowness something you allow yourself?
- 6. Thoughtfulness is the time necessary to reflect on decisions. How do you ensure that you do not make decisions too quickly and that you are thoughtful?

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CHAPTER 3 "I'M ONLY HUMAN"

MEDIOCRITY AS A STIMULUS FOR GOOD-ENOUGH CARE

In her novel, *There Used to Be a Future (Vroeger was er later)*, inspired by the final year and a half of her father's life, Vera Marynissen (2012) puts herself in the position of Paul, an elderly man in a care facility. Snippets of a life story are punctuated by the unembellished reality of life in the care facility. An interesting excerpt is the meeting between the first person, Paul, and Marieke, a carer in training. Marieke doesn't quite fit in with the string of caregivers that Paul without exception calls "sister". She dances into Paul's room in a patched uniform and her playful and spontaneous manner has a contagious effect. She tells Paul that she would have preferred to become a dancer ...

"... but I wasn't allowed to. 'If I'm not allowed to dance, then I want to help people', I said. And that was okay."

She chatters, and chatters, and chatters. Her mouth moves, her hands move, she flits around and around in her darned "nurse's" uniform.

"Besides, old people aren't dangerous", she says. "And it's good to help people."

I attempt to readjust the cushions in my back unnoticed. "Helping people is a good thing, but you have to have the knack", I say. She puckers her eyebrows.

"Some people can't be helped", I say. She shrugs her shoulders.

"Some people don't want to be helped", I say. She shakes her head.

"Some people say things to tease", I say. She smiles.

"Now I have to get a move on. Would you like some coffee? Coffee and a biscuit?" "With two biscuits", I say. "With lots of milk and half a lump of sugar." (I always take my coffee black and without sugar).

- Marynissen 2012:123 (authors' translation)

Paul teases. Teasing is asking for love, or, at the very least, asking for attention. It seems here that Paul is calling attention to his situation in which no one can really help him, whatever caregivers do or however good their intentions. Some people just can't be helped, even if they do really want to be helped. It is as though Paul in his teasing wants to protect the endearing, naïve Marieke from entertaining too high expectations in her "wanting to help people". It is as though he wants to point out to her the mediocrity that every caregiver runs into sooner or later: the sobering experience that you are average.

In the desire for a technically perfect world, mediocrity is not acceptable. But idealism is not always realism. In a world known for its deficiencies, mediocrity may take on a new meaning and appreciation. One of the appropriate questions to be asked is: What exactly is this experience of mediocrity? And what does it mean in the pursuit of good care?

Mediocrity in care because people are suffering

Despite all the good aims and intentions entertained by caregivers to go beyond mediocrity and go after what is best for the patient, their care still remains at times below par – and it is therefore inadequate. This is mediocrity of care. It is a mediocrity that is typical of care because caregivers are after all only human. They are, after all, not God. And this means that they do not always perform perfectly in difficult situations, do not always have time for everything, cannot always bestow their complete attention on everyone and cannot always keep their cool. "They're only human" is at times the response. This simply means that they are also vulnerable. They are liable to error and are imperfect. This latter is also related to the far from ideal context in which care is offered, which also fosters mediocrity. The care context is often characterised by lack of time, inadequate communication, and shortage of people and resources.

Suffering of an excessive nature

When Paul points out in a teasing way to Marieke the fact that some people cannot be helped, he is indicating another reason why care could be under par. Whatever they do and whichever means they employ, in situations of excessive suffering in particular, caregivers are not able to remedy or provide comfort for such suffering. Such excessive suffering has to do with unbearable physical pain that goes on unceasingly and which can barely be held in check. The Parkinson's patient Xavier Thévenot writes of this in his spiritual dairy:

I have just endured two hours of excessive pain, making it impossible for me to concentrate on anything whatsoever: reading, music, conversation, and so on. At such moments all my attention is overwhelmingly consumed by the organ undergoing pain. As if that was all that existed and screamed at me: "Think of me! Relieve me!" It is the cruel confirmation of the philosophical truth about the intimate relationship between our self and our body: I am the organ that is in pain, and my whole being is forced to be preoccupied with it. Yet I am in pain, in the sense that I am much more than that little bit of my life: it is in me and belongs to me and is me all at once. At the moments that this pain racks me, I feel like a wounded animal, lured into a trap. I look for a way of escape and cannot find one. It makes me despair.

- Thévenot 1997:97 (authors' translation)

Excessive suffering also relates however to the continual experience of pain that may not necessarily be so intense, but which is unceasing, or which may suddenly and unexpectedly surface. This sort of excessive suffering is not a question of continually experiencing great pain; it is rather the cause of people feeling that they can no longer live a normal life. They can in all events no

longer lead the life they want to lead because of the constant consciousness of pain. Excessive suffering is therefore not necessarily a question of the quantity of pain that someone has to deal with or the intensity of the suffering or even with purely physical pain. Excessive suffering is the experience of pain or discomfort or ageing or nausea, of which people do not want to be conscious, but which insists on its presence in everything.

Paul, the first person in the novel, is not in any sense a terminal patient, and he does not suffer physically to an unbearable extent. And yet, he does suffer excessively, not so much quantitatively as in his experience. He suffers from his physical deterioration, from being able to do less and less, from being less and less mobile, and from his dependence on unfamiliar caregivers. Paul no longer lives the life that he wants to live, but endures a life that he does not want to endure. He experiences his suffering as excessive in this sense, as a river that overflows its banks and disrupts his life, even if he is not dying from it. Paul, the character in the novel, muses on his relationship with the caregivers in the residential home:

They think that I need help to grow old. Everything went smoothly on its own for a long time. Until people started to interfere. Up until the day that Anna became ill. And this is the result: I am lying in room number 264, a room with a plastic roll-down shutter between the bed and toilet, with things from home that somebody else has picked out for me, which are unable to conceal the fact that this room is the same as that of the poor woman in room 276, and which have become unfamiliar objects since their removal here. "Cosy! Things from home!" They cut off a person's leg and then use it as a prosthesis.

Marynissen 2012:76 (authors' translation)

Everything seems foreign to Paul, even his own body. What you used to take for granted, namely a healthy body, now shows its unreliability and complete fragility. As a result of the deterioration, he no longer recognises or trusts himself. His body no longer seems to belong to him; it is an unfamiliar body. It does things he doesn't want it to do. For Paul, growing old is like trying to walk in a straight line when drunk. His life has taken a course he does not want to take, and he can't make any adjustment to it. He is no longer at the helm. He has no other choice than to endure it, knowing that it will not get any better, only worse.

What characterises Paul's excessive suffering – and every sort of extensive or even light suffering that makes itself felt as excessive – is that it puts one off one's stride. He suffers from the past which cannot be altered, and the way things have turned out in the present: *rien ne va plus* (nothing works any

more). He suffers from the present that has nothing else to offer than one senseless activity after another. He suffers from the future that has nothing else in store than further deterioration and ultimately death. Paul experiences life as senseless. "I don't come from anywhere. I am not going anywhere. I don't belong anywhere." For Paul, growing old in a residential home means waiting for death, exposed, for all the world to see. This experience of meaninglessness is especially intensified by having to lie in wait, by being condemned to a horizontal state. In this sense, Paul also suffers from an existential decubitus, namely a sort of hole in his being as a result of having to lie for too long a time, waiting for nothing in the future that is still to come. Only those who look closely will see Paul's suffering. His inner wound is not as visible as his physical bedsores. Here, excessive suffering is not a question of overwhelming agony, of a surplus or too much. It is not the physical intensity of the pain that is unbearable. His suffering is excessive because it throws him off balance and makes everything confused. It is excessive suffering because, even if it is not quantitatively great suffering, it is always present and makes Paul experience what he absolutely does not want to experience.

Suffering escorts the caregiver and the care-receiver into separate worlds

Paul's story brings out his suffering, which is a different suffering from that of any other person in the same residential home. Not every elderly person in a care facility suffers to such an extent for that matter, even in the context of many experiences of loss and confronted with deterioration. No two people undergo the same suffering. Every person who suffers, suffers in his/her own way. That is precisely what makes the suffering so acute: that it encloses the person who is suffering within him-/herself and in the unique experience of pain that is endured totally alone. Suffering is accessible to no one beyond the person suffering, intensifying the suffering because it condemns the suffering person to the utmost loneliness. There is no sympathy, no empathy that can put a stop to the suffering. This inaccessibility creates the acuteness of the suffering. It locks the suffering person up in him-/herself. What you cannot share with another, you have to bear all alone. If this sharing is not an option because it is impossible to precisely articulate the suffering you are undergoing, then your suffering actually increases.

However, the caregiver also has a problem. As indicated in the first chapter, care is always founded on empathy and on a form of compassion. The ethical involvement with the other does not begin with a rational decision, but from being touched or moved by the suffering of the other. The inaccessibility of the suffering is however an obstacle for this empathy because it is impossible in such situations to even begin to feel what the other is feeling. Caregivers are

confronted here with limitations: however skilled and proficient they are, their empathy is truly inadequate. This is not at all as a result of a lack of will-power or thoughtfulness; it is a question of not being able to do so. Caregivers find themselves unable to provide good care because it is not possible to empathise enough with the other's suffering. However, involved they are with their careseekers, and however caring they are in their relationship with them, caregiver and care-seeker still remain separated from each other. Through suffering they remain radical different for each other (cf. Chapter 7).

Mediocrity causes suffering

The mediocrity mentioned here has everything to do with the experience of human finiteness and the confrontation with limitations of knowledge and what is possible. *Mediocrity is truly the experience of falling short of the mark, as a consequence of the otherness of the suffering of the other, and this is not the result of a caregiver's shortcomings.* It is always possible to do something about the latter. Caregivers can for example acquire skills or improve the context in which they give care. When failure in care is however the result of suffering, regardless of one's caring skills and competencies, there is nothing that can relieve the person's suffering since the suffering is such a personal experience. In actual practice, this form of mediocrity causes a tremendous sense of powerlessness among caregivers as well as among care-receivers.

Marynissen's novel *There Used to Be a Future* tells how the caregivers – both Paul's daughter and the caregivers in the care facility where he lives – attempt to imagine Paul's suffering, but they come up against the limitations of their empathy. They try to compensate with a sort of acting-as-if they understand Paul. This though is a form of hypocrisy. (In the next chapter we will look more closely at 'hypocrisy'.) The novel also shows how the caregivers do their utmost to alleviate Paul's suffering, but how they in and through these efforts only become more distanced from him. The result of this is that Paul feels that everyone has the best intentions towards him, that they do their utmost, at all costs and against their better judgement, just to create hope. Everyone treats him with so much caution that he feels himself to be even more fragile than he already is. Lying on his bed, Paul muses:

Look! That man on the bed: that's me. On my back there is a sign: "FRAGILE!"
On my forehead the inscription: "BREAKABLE!"

Around my neck a placard: "HANDLE ME GENTLY." Handle with care! Be careful! Be prepared!

- Marynissen 2012:147 (authors' translation)

However good the intentions of the caregivers around him, Paul feels he has been let down in his suffering. In his experience, everyone is pussyfooting around him and acting-as-if there is no suffering at hand, as do the alwaysfriendly caregivers in the residential home who are so totally committed to caring for his defective body. They do it with a cheery determination, showing that they can deal with it, that they can get the better of it, even if that cheery determination comes across to Paul as indifference, even if as far as he is concerned, they haven't mastered anything, since when they have completed their care activities, he feels no better at all. Sometimes only worse. We read an example of this when Paul has a mishap in the toilet. "We'll give this piggy a good wash!" is the well-intended reaction of the caregiver. "Don't panic!" The piggy gets a wash with the aid of nappy-liners. It is not so much the nappyliners that disturb Paul, but rather the reaction, as if all the misery has then been dealt with. Being washed is similar: Paul is powdered like a baby, as if the smell of an elderly person is thus dispelled. The false hope that they give him in the way they act, as well as in the frequently repeated "all will turn out well in the end", that it is really not as bad as all that, force him to keep his suffering and despair to himself, so much so that his suffering is only intensified.

Even if it is *only* a novel, the way in which the caregivers deal with their power-lessness corresponds to what actually happens in real life. Mady Cuypers, a nurse, remarks in her book on powerlessness in care that caregivers often try to compensate for their powerlessness by seeking fulfilment in the things they can aspire to with certainty:

The more complex or intensive the caregiving is, the greater the fulfilment. Washing someone is routine, but if you can take care of a wound or take a blood sample at the same time, or can do a first class job of looking after someone, this creates a sense of satisfaction. This is not so surprising since technical activities are almost the only matter about which the caregiver has any certainty. During one's training, due attention is given to learning technical skills. You are assessed on that basis and ultimately you begin to assess yourself as a caregiver on the basis of your techniques. You know at least as far as these are concerned when something has been done well.

- Cuypers 200:29 (authors' translation)

Caregivers do not like to admit to themselves that they feel powerless in a situation. This would not be in keeping with their professionalism as caregiver, nor with their dignity as carer: caregivers have to be able to keep going in care. Since most caregivers are practical, they seek some grip on their work through the careful execution, according to the rules, of technical care activities. The familiarity of daily care offers them at least the illusion that they can postpone the suffering of the other for a while or even bring it to

a stop. The (often unconscious) glossing over of mediocrity by caregivers is the reason why care-receivers often feel even more left in the lurch. This is certainly so in Paul's case. It is striking how, in the novel, Paul identifies the determined performance of the caregivers as indifference. The well-intended and respectfully performed care activities lead to an intensification of his sense of having been abandoned and of loneliness. This is accompanied by a sense of being more and more alone and abandoned, with the worsening of his physical illness in consequence, and at the very least, the feeling that he is deteriorating or getting worse.

Finnish research conducted by Stenbock-Hult and Sarvimäki (2011) into the vulnerability of nurses who care for the elderly indicates how some caregivers become more and more indifferent and perform tasks routinely, precisely because it helps them to keep going in care provision. Others cling tyrannically to all sorts of rules and procedures in order to be able to continue to feel good about their work. Other caregivers continue to be vulnerable, but often suffer from a frustrating feeling of guilt that they are falling short of the mark. Some nurses have sleepless nights over the question: "Could I improve what I'm doing?" Nurses participating in a Finnish research project on vulnerability, communicated how frustrating and stressful it is to experience in certain situations in which they are trying to get a grip, that again and again the ground is cut from beneath their feet.

The same research brings yet another way of dealing with mediocrity to light. Some caregivers experience that they are able to develop an area of strength in care precisely by recognising mediocrity. They explain that becoming aware of their own limitations as a caregiver is an important issue for them, making it possible to keep going in care, but also enabling them to offer good-enough care. The recognition that they cannot help the other's suffering relieves them from the peremptory duty to do something at all costs. In this way, it is easier for them just to be with the other, sometimes as helpless as the patient him-/ herself. It makes it possible for them to be vulnerable, to experience sorrow in what the other is going through and in that way to be closer to the fragility and the hurting of the patient. Moreover, a number of nurses involved in the research mention how the recognition of their mediocrity is also a starting point for further development. By recognising that they do not actually succeed in giving good care they begin, in their own words, to reflect on that care and on attainable goals in care and in this way good-enough care becomes more of a reality.

Mediocrity as small vice in care

Up to now, mediocrity has appeared as the finiteness into which caregivers run. Mediocrity is sketched not only as being a (frustrating) given, but also as a vice. Mediocrity makes an appearance then as a more or less disguised form of detachedness or indifference. Or even as an expression of a refusal to be truly involved with the other. Mediocrity is also considered as a vice in ordinary day to day language, namely as a sort of behaviour that is unacceptable, a type of moral half-heartedness. The paradox that we now wish to propose is the following: mediocrity can be exercised in such a way that it has a positive effect on both the caregiver and the care-receiver. Seen from this perspective, mediocrity in caregivers is a kind of pursuit of care that is achievable or care that is adequate within certain boundaries. Mediocrity means in this case that caregivers can keep going in care, without becoming fanatical or despondent and thus without the ethical pursuit of good care becoming destroyed, rather to the contrary.

Letting go of what is not attainable

Caregivers realise through the powerlessness of this unavoidable mediocrity that the task they have given themselves – to do the very best for the careseeker – is too difficult to live up to. Gradually they realise that only the *desired care* can be the best possible care. As mentioned, caregivers can try to ignore this powerlessness, but they pay a price for this, as does the care-seeker. Another possibility is that they recognise their mediocrity and accept it. This means not only that they accept that they *cannot* achieve the very best, but also that they *do not have to achieve* the very best. As demonstrated by the Finnish research, this acceptance creates possibilities to keep going in the care process, as well as for taking on responsibility in a realistic way. Nothing is more paralysing than high ethical ideals that cannot be fulfilled. If caregivers succeed in reducing those ideals to realistic and attainable proportions, then they will feel more able and better prepared to take responsibility for what they do.

Mediocrity as a lever and as small virtue is an indication of the level-headedness with which caregivers, in their disappointment and frustration about what they cannot achieve, reflect on what can be done. This means that they remain motivated to go on providing good care, but they adjust their objective and look for attainable means to reach it. We call this sort of common sense level-headedness. It is a sort of down-to-earth approach that takes reality into account to the extent that it assists the caregiver to find the right measure of care, namely one to be found between the unattainable ideal of realising the best possible care and not realising anything. Mediocrity is then not a

type of cynicism or indifference, for the challenge of looking for what can be improved remains key in care. However, the fanatical pursuit of what is best for the patient gives way to a greater sense of reality. Level-headedness is concerned with determining an attainable goal, but also with determining the right and realistic means to achieve this goal.

We need this level-headedness precisely because we are only human. A god would not need it. Since the suffering of the care-seeker cannot be taken away, and/or because caregivers are limited and yet want to provide the best possible care in situations where the means and possibilities are not available, they are then obligated to think carefully through what those means and possibilities are. It will not succeed with love and good intentions. Common sense and insight are necessary to achieve that goal. Level-headedness is the art of taking everyday reality into account: it is the ethics of the attainable.

But there is a condition: the caretaker should engage with his/her own shortcomings and weaknesses. The problem is not to be inadequate or to have limitations. The difficulty is to accept it as norm and therefore acceptable behaviour. Many deteriorating healthcare systems relate to the unchallenged acceptance that something cannot change. It is human to challenge the current state and to commit to improvement.

Modesty

Suffering cannot be erased or washed away. The awareness of mediocrity brings us to modesty. Caregivers accept that the best care may not be possible given specific circumstances. It is precisely this insight into the limitations of their own capacity and those of the context in which they provide care that gives them strength to pursue what is attainable, without allowing themselves to be tempted by cynicism or laziness. Decent care – as the most attainable care – demands modesty in as far as caregivers pursue what is attainable on the basis of the insight that the desired or ideal care is not attainable.

Following Comte-Sponville (2002), the philosopher Spinoza taught that the insight of being limited and mediocre always creates some sense of sadness. It is the sadness that a person is only him-/herself. It is the awareness that you are not God, are not even an angel. For Comte-Sponville (2002) this is not a paralysing but rather a liberating sadness: a person can do no more than be him-/herself and take courage from that. The sadness of modesty is moreover not a bitter sadness. It is rather a form of kindness or compassion toward oneself: caregivers can be content with who they are and with what they do. They can only do what they are able to do and can leave what cannot be changed as it is. This is why, for Comte-Sponville, compassion and modesty always go together and complement each other. Modesty is accepting oneself

– but without deluding oneself. Modesty is: no longer seeking to attain what is not humanly possible.

This modesty is imperative to help caregivers to avoid turning their backs on the other. Only when caregivers are aware of the limitations of their own capacities do they find room for the other. They find it easier to accept the boundaries with which they are confronted in regard to the care-seeker. They become milder toward themselves and toward the other. According to Augustine, where there is modesty, there is also love for one's neighbour. Modesty keeps caregivers from turning their back on the other, even if they don't come up to the mark. Modesty is the attitude of keeping one's focus on the suffering of the other, of letting go of unrealistic dreams in which all suffering is erased, precisely in order to come closer to the other. We don't have to play at being God, or even being an angel. Besides, as Blaise Pascal (1977:337) once wrote: "he who wants to play the angel, plays the beast", by which he meant that we become very tyrannical when we cannot accept our own mediocrity.

Room for goodness that is good-enough

Sometimes caregivers do not even succeed in providing decent care or goodenough care, however much they reflect on seeking to find the achievable means. This is very possibly the case in Paul's situation, for whom no one seems to provide care that is good-enough to alleviate his suffering. No one? Not entirely. Marieke seems to succeed in drawing Paul out of his misery a little. Not so much by what she does (or doesn't do), but rather through who she is through being her spontaneous, playful self. She has a daily conversation with him that, precisely in its banality, is very different from all the other conversations that other caregivers have with him. It is a conversation in which Paul does not feel himself to be treated with the customary cautiousness because of his fragility. It is a conversation between a young woman and an old man, not even a very lengthy conversation, with much humour, in which they tease each other, and one in which Marieke tells Paul that she would rather have become a dancer than a caregiver. And then she disappears again, after having given him coffee and biscuits – two, in fact! She doesn't appear again, as if Paul had dreamed her up, but even then, she did draw him briefly, very briefly, out of his suffering, without ever having made a real attempt to do so.

It seems as though Marieke introduced a little bit of goodness, but big enough all the same to briefly alleviate Paul's suffering. In all this smallness, a little bit of goodness is preserved. The philosopher Levinas also writes of this. He says that:

... in the midst of all the decay of human relationships, goodness persists. It remains possible in the relationship of one person to the unique other, even if it can never be completely organised. The only thing that vivaciously remains is the small goodness of daily life. It is fragile and tentative. It is a goodness without witnesses that has taken place in silence, modestly, in passing and without triumph. It is given freely and is, in consequence, eternal. It is ordinary people, simple souls, who defend it or keep on exercising it without adamantly defending it. Unnoticed, they ensure that it always gets going again, even if it is totally defenceless. This paltry goodness struggles upright, like a trampled blade of grass that doggedly, but silently, once again straightens up. It is possibly mad – a foolish goodness – but it is at the same time the most human aspect of humanity. It determines, or rather inspires people, in spite of their powerlessness. It is beautiful in its powerlessness, like morning dew. It never wins, but it is never conquered.

- Levinas 1995:116-119 (authors' translation)

The goodness that does not lose its footing in the face of excessive suffering is so fleeting and small, and in the light of good care so banal, that Levinas rightly speaks of "small goodness". It is namely nothing more than a little bit of goodness, a moment in which good lights up, so much so that it briefly alleviates, momentarily postpones, the suffering. The small goodness is essentially a gift, both for the care-seeker and the caregiver, because it is made possible in spite of the latter. What is characteristic of this small goodness is that it cannot be willed, let alone organised. It cannot be summarised in procedures and regulations. It can only come to be in the relationship between two people, in which one just does something for the other, without deep reflection on what it will lead to, without the intention even of bringing about some good, and particularly without concocting great plans and strategies to achieve the very best. What the caregiver does is much too small for this, much too fleeting, much too fragile. The small goodness is to be found in very ordinary things that characterise day to day relationships without attracting much attention. It's even a little difficult to call these things small goodness.

The small goodness is brief comfort without offering the promise of improvement. Marieke draws Paul very briefly out of the isolation of his suffering without creating the impression that this will make everything better. In this small goodness, the caregiver does not take refuge behind all sorts of activities, in the illusion that the suffering of the other can in this way be erased. By abandoning the illusion, the caregiver becomes able to draw closer to the care-seeker. There is, in other words, no other aim or intention than that of being there. Levinas again provides us with a good application of such a small goodness in care for people who are suffering excessively through deterioration, loneliness, illness, growing old or exhaustion in what he writes

about the caress as touch that is almost not touch, but only a slight brushing of the other. He writes of this caress as comfort:

The caress of the person who comforts and carefully touches the person in pain does not promise that the pain will disappear and neither does it announce any compensation (for the difficulties). Comfort that is worthy of that name has in its contact nothing to do – on the basis of guarantees [something for something] – with later. It does have to do with the moment of pain itself, with the here and now, so that it is no longer condemned to itself. Through the movement of the caress, the pain is carried elsewhere and is in this way freed of its oppressive oppression and through which the pain is given a breath of fresh air and, literally, room to breathe. Suffering is in this way redeemed from despair: a form of resurrection in the here and now through which the same is made to differ. Such a consoling caress is infinitely mysterious: something which we do not sufficiently allow to amaze us!

- Levinas 1978:156-159 (authors' translation)

A care-seeker who is washed in this way, where the touch has more affinity with a caress than a cleansing movement, may experience this as a small goodness. In the touch of the caress, the pain will not be taken away, but comfort may perhaps be experienced, if but briefly. What is striking with this sort of comfort is that it does not suggest any illusion of recovery to the other (or to ourselves): "Take comfort, tomorrow will be better". This is exactly the sort of false hope to which Paul in the novel There Used to Be a Future has such a deep-seated objection. Tomorrow it will not be better at all; in the best case, tomorrow offers more of the same. The comfort of the caress of which Levinas writes is another sort of comfort. It is a comfort that places itself in the now of the other's experience of suffering and cautiously touches him/her, and comes close, in the here and now, without empty promises. It is then also a mediocre comfort, the comfort of the small goodness, the comfort of a cup of coffee at a funeral, which in no way takes away the loss and is so fleeting, but which does leave a different taste in the mouth than that of death. Especially when accompanied by a biscuit. Or two.

Care incentives

The following questions and activities can guide the caregiver in dealing with mediocrity:

- 1. Do you recognise the feelings of powerlessness in the care process described? At which moments do you feel most powerless? How do you react to this?
- 2. What avoidance strategies (such as starting to talk about something else, going away, mollifying, etc.) do you resort to, to get away from the other's suffering and to not feel your powerlessness?
- 3. What effect did it have when you did stay with someone to be close to them in their suffering? How did this change your relationship with that person?
- 4. In which circumstances did you take the time to reflect on the other's suffering? How do you feel about disregarding the other's suffering? What feelings does this involve?
- 5. How do you react to the inaccessibility of the other? Do you cut yourself off or are you able to look for a chink in the other's wall of rudeness and self-concealment?
- 6. Think of someone whom you see suffering, a suffering that makes you feel powerless. There is no other option than to dwell on this suffering. Give an example of what is attainable (small goodness).

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"I DON'T ALWAYS SAY WHAT I THINK"

HYPOCRISY AS A MEDIATOR OF CARE THAT REMAINS HUMAN

The Dutch neurologist Emile Keuter wrote a column about all the emotions that a caregiver experiences during the course of one day. In a hospital there are as many varied emotions as there are varied situations. Caregivers are expected to respond *appropriately* in all of those various situations, but how should appropriately be understood? Keuter describes the situation in which he, as a doctor, felt tears running down his cheeks for the first time. He was at the deathbed of a young man of his own age. The young man died after a motorcycle accident and weeks of intensive care. Keuter writes of the tears and of the next patient he had to visit, who had nothing to gain from those tears, and in whose presence he did not wish to exhibit the feelings he had experienced with the previous patient. And then a surprising passage in the column follows. Keuter writes:

What we do as doctors is actually a little bit of acting. The people who can act well are better doctors. It's a combination of the deep-acting [in which feelings are expressed that are not truly present] and the surface-acting [in which only the expression of feelings is adapted to the situation], of for example Meryl Streep and Arnold Schwarzenegger. We are actors who stand and cry along with the family, and then move on to the next act.

- Keuter 2013 (authors' translation)

What Keuter calls acting can be understood as a form of the verbal and non-verbal communication that caregivers use to deal professionally with the suffering of care-seekers and to spare them. It may possibly even be a form of empathy. They try to adapt professionally out of empathy with the other's suffering and insight into what he/she is going through, even when this adjustment demands of them that they do not show completely – or do not show at all – what they are really feeling or thinking. In the case of the latter, they do indeed come close to acting.

The form of verbal and non-verbal communication that Keuter simply calls acting is in his opinion both unavoidable and necessary. He gives two reasons for this. The first reason is self-protection of the caregiver: without it you won't survive in caregiving. You cannot after all continually overload the limbic system, namely that part of the brain that regulates the emotions. The second reason that Keuter gives is that it is through this form of communication that you express your closeness to the care-receiver. Put succinctly, this means that it enables the caregivers to be distantly close. And to remain adequately professional. Keuter's remarks is important: whilst you are doing all you can for a person you can only do it if you care for yourself. One can thus say that care for others is only possible on the basis of self-care.

Maintaining professionalism is not always so simple, nor is finding the balance between keeping a distance and proximity. This demands of caregivers that they sometimes express other feelings than those they actually have or to say something other than they actually think. The objective truth sometimes comes off badly. How far can you take this? And is every form of hypocrisy or dissimulation in care altogether wrong?

Hypocrisy or good care: irreconcilable?

There are of course various sorts of acting-as-if that are employed not only for many and various reasons, but that also differ considerably in quality, namely between a little bit of acting-as-if and a lot of acting-as-if. Caregivers can then relate to someone they do not like very much in a friendly way, or they can lead a resident to think that he/she will only be staying very briefly in the nursing home because they do not want to make it even more difficult for the family that is already having such a difficult time. Or they allow a patient (and his family) to believe that the patient is better, while they know very well that this is not the case, but they do not want him/her (or them) to give up hope. Or they do what their colleagues think is important, although they do not completely endorse this view themselves, because, all things considered, a good collegial atmosphere is better for the patient.

Many caregivers feel that acting-as-if is acceptable and permissible, that it is even necessary in order to be professional, as long as it doesn't become hypocritical. So when do we speak of hypocrisy? When is hypocrisy wrong? It is a loaded term, because it seems as though hypocrisy involves condemnation. Nobody likes to be called a hypocrite or wants to see oneself as a hypocrite. People who are hypocritical give the impression of something without being in complete agreement with it. This is possibly the reason why caregivers do not want their professional acting-as-if to be conceived of as hypocrisy. If this word is used, it is immediately repudiated by many caregivers. They do not want their credibility – and with it their integrity – to be in any way put at risk. But does hypocrisy call this credibility and integrity into question? Posing the question about the possible relationship between hypocrisy and good-enough caring in any case creates a shock effect that sets people thinking.

Narrow and broad hypocrisy

Hypocrisy was not always a loaded word. The history of the word hypocrisy goes back to the theatre of ancient Greece where it was used to indicate a person who spoke "under" (hupo) or "separate from" (krinein) the chorus. Hypocrisy in this context is still a neutral term, although we do find something of the

contemporary charged meaning of the word. In Greek theatre, "hypocrites" designates the actors who are acting-as-if, and who say things that they do not really mean, for example those who act as if they are jealous on stage, or as if they kill someone out of jealousy. Today we simply call such people actors.

In the course of history, the term hypocrisy has gained a certain moral charge, and a rather negative moral connotation. The word appears in the New Testament (see Matthew 23:27) where Jesus calls the Pharisees – exemplary figures in terms of good behaviour and character – "whited sepulchres" and "hypocrites." Here we possibly find the origins of many synonyms for hypocrisy, dissimulation and insincerity. Hypocrisy is the designation given to people who act as though they are holy. Something lurks behind that holiness – the piousness or religiosity or legalistic scrupulousness in the case of the Pharisees – that is less holy, or less wholesome. They feign certain feelings, values or virtues without living them out in their lives, while they criticise others on the basis of their acting-as-if. The holiness that they feign in and through maintaining laws and rules serves to uphold their reputation and gain esteem.

Narrow hypocrisy as deceptive dissimulation

In this last sense, hypocrisy – as dissimulation and insincerity – represents a questionable sort of behaviour. It is a form of deception employed purely in order to make a better impression and to dominate others in consequence. Hypocrites mislead through an outward behaviour that is inconsistent with their intentions: those intentions or convictions are much less virtuous than the impression they give through their behaviour. They appear holier than they truly are and under the guise of virtue they are able to manipulate and use others for their own power and profit, with the intention that their observers do not see (or recognise) this.

Self-interest and selfishness are concealed behind this sort of hypocrisy. This is dubious, but not necessarily reprehensible. In Nazi Germany there were Jews who posed as Nazis in order not to be exposed as Jews. The film *Schindler's list* shows how Schindler's hypocrisy – he gave the impression of being more supportive of the Nazis than he actually was – saved lives, although it initially concealed his own self-interest. This sort of hypocrisy does become reprehensible when others are manipulated on the basis of pure self-interest, personal enrichment or display of power. Such is the deceptive dissimulation represented by the personage of Tartuffe in Molière's play of the same name. Tartuffe seems to be a devoted clergyman, but is one who uses the trust others have in him to enrich himself and give free rein to his passions. Tartuffe is the literary example of deceptive appearance.

Examples of deceptive appearance in care come up in situations involving unwanted sexual behaviour. In these situations, professionalism is feigned in order to draw the other into the sexual sphere of influence and the person suffers the highest level of deception. In this way, the psychiatrist who abuses the therapeutic trust to bind a client to him-/herself and to approach her/him sexually or to seduce her/him, concealed by the appearance of respect for the deontological criterion of *informed consent*, is a clear instance of reprehensible hypocrisy. For this reason, as counterweight for deceptive appearance, we will give attention in the fifth chapter to the idea of *parrèsia* (Foucault) as bold communication in care. Although this will deal in particular with speaking boldly on the level of the care organisation, boldness is also necessary in the care relationship itself. If that relationship is based on trust, then uninhibited openness and frank communication is possible. This of course needs to be accompanied by the necessary caution and without slipping into a ruthless harshness.

The "acting-as-if" that Keuter (2012) mentions, in combination with the cited daily examples in care, is a far cry from the narrow hypocrisy of deceptive and disrespectful dissimulation. This is not a question of the manipulation or abuse of the other. In this context the patient is not misled in a morally perverse way. At most, the patient's illusion is left unspoiled. Furthermore, the caregivers in the examples do not have the intention of harming the other for their own gain. The doctor who feigns certain feelings does perhaps want to give the impression of being a good, professional, sympathetic doctor. The doctor does not only want to give this impression, he/she also wants to be a good and virtuous doctor. And he/she wants to persist in being so, and also to be so for every patient. That, in fact, is the reason that he/she sometimes acts-as-if.

Broad hypocrisy as a mild form of acting-as-if

This acting-as-if relates more to what could be called broad hypocrisy, namely a type of hypocrisy that everyone makes use of once in a while – if not daily. With the exception of misleading and manipulating dissimulation, there are also the false appearances that people maintain with a social intention, namely the intention of wanting to belong. People act-as-if to give the impression that they are better than they actually are so that they can feel better about themselves, to protect themselves from shame or rejection, to avoid being hurt, to maintain their self-respect and their affection for others, or simply for their own comfort. In general, people make use of a broad form of hypocrisy in order to lead a comfortable social life and in order to keep on good terms with others.

A television series such as *Keeping up appearances* thrives on this form of hypocrisy: acting-as-if with a social intention. The hilarious Hyacinth, whose

name is actually Bucket, but who insists on it being pronounced *Bouquet*, goes to great ends to gain acceptance in higher circles, or rather, to be considered by those around her as belonging to the better classes. She portrays, in a sublime, caricatural and exaggerated way, how this seeking to give the impression of being better than we actually are beguiles all of us from time to time. The exaggeration of this magnificent, ludicrous self-deceit as an innocuous form of hypocrisy that is easily recognised by observers makes the viewer laugh and chuckle without sarcasm.

Besides this ludicrous hypocrisy that is based on a person's own image, there is another form of relational and social hypocrisy. People sometimes dissemble, not for themselves, but on behalf of the other. This too is broad hypocrisy, a form of hypocrisy that is characterised by mildness and generosity toward others, with the intention of not being too confrontational in relating to them. This kind of hypocrisy is used in order not to hurt people or to embarrass them intentionally.

In contrast with narrow hypocrisy, this broad approach to hypocrisy concerns the misleading of the other in a more or less acceptable way, with the aim of making continued co-existence with the other possible. Broad hypocrisy is employed in and on behalf of the relationship with the other. Imagine if people always said what they actually thought, were always completely honest and never kept things to themselves: living together would be a kind of hell. Everything would be predictable. Society would be a raw, brutal and blunt place. Without this broad hypocrisy, "the law of the jungle", the one who shouts the loudest, would dominate. We touch here on what Emmanuel Levinas calls "the rhetoric of the anti-rhetoric." He says that:

A new sort of rhetoric asserts itself as an anti-rhetoric: the battle against eloquence. A hidden false appearance that rejects all false appearance, in search of a confrontational language: harsh rather than polite, vulgar rather than elegant ... [...] The aim is to recover sincerity ... without sparing the other. People assume that the greater the directness, the greater the sincerity will be ... without realising that it concerns a bombastic sincerity that disquises its terror.

May-be eloquence is too good to be true, but may-be the battle against grandiloquence is also too awful to do justice to the truth and the other!

- Levinas 1987:207-209 (authors' translation)

If we want to be completely rid of all false appearance and rhetoric or empty eloquence because sincerity or transparency has to be the dominating ideal, then, according to Levinas, a form of intimidation and terror is created. Furthermore, we then think that we are sincere, but this is actually also a form

of false appearance. It has to do with a false appearance that veils itself in the clothing of sincerity and transparency, although it involves an implacable honesty. This is why hypocrisy as broad hypocrisy is not only a fact, but also a necessity.

Broad hypocrisy: sometimes a necessity for and sometimes an obstacle to good-enough caring

The acting-as-if in the above practical examples and the acting-as-if of which Keuter speaks have much to do with the intention with which people resort to broad hypocrisy. Caregivers act-as-if precisely out of consideration for the other, to spare the other, so that the care relationship does not become a hell and to avoid adding more suffering to the suffering the care-receiver already has to endure. The term hypocrisy is therefore not used judgementally in reference to these forms of acting-as-if. It is not in reference to an immoral form of dissemblance or acting-as-if – as is the case with narrow hypocrisy – but to a form of professionalism through which caregivers seek a distanced proximity.

Hypocrisy as a form of respect

Think of *Summer House with Swimming Pool*, the novel mentioned in the first chapter on antipathy (see Chapter 1). The doctor was initially able to channel his emotional prejudice toward people – his antipathy – through acting-as-if. He was courteous, polite, even friendly, but this was a bit of a put on, certainly in relation to those patients toward whom he entertained feelings of antipathy. When he is no longer able to act-as-if, his patients leave his practice.

The politeness and friendliness with which the doctor suppresses his spontaneous antipathy signifies the beginning of respect for the other. This involves a mild, sly and small type of false appearance or light-hearted hypocrisy that takes the fragility of the care-receiver into consideration. If the acting-as-if is an expression of demagogy, arrogance or abuse of power, then the doctor enters into an immoral type of hypocrisy.

In the novel *The Old King in His Exile* in which Geiger writes about his father with dementia, we again find an example of dissimulation as a necessity and as a way of expressing respect for the other. In the novel, Geiger reflects on the slowness of the process of care for his father and tells of the insights which developed during the course of that care process, insights which would not have been possible without the slow pace. One of these insights has to do precisely with hypocrisy. This is reflected in the following fragment.

Everyday interactions with him were increasingly like fiction. We accepted all the faulty memories, paranoia and workarounds with which his mind

defended itself against the hallucinations and everything else it didn't understand. The only remaining place where we could be together was the world as he understood it. We would say everything we could to affirm his sense of things and make him happy. We learned that holding sanctimoniously to the truth was the worst approach of all. The truth didn't get us anywhere – it served no one well. To give someone with dementia an answer that, according to the usual rules, is objectively correct, but which pays no attention to the place where the person finds him- or herself, is to enforce a world that isn't his or her own.

- Geiger 2017:117-118

Truth's dissemblance is sometimes the worst of all. This is a remarkable paradox. It is a paradox that is based on the distinction between the reality of the caregiver on the one hand, and the reality of the person with dementia on the other. We often call the former "the only true reality" or "the objective truth." Geiger is saying here that, from his father's perspective, this objective truth is hypocritical. If the caregiver swears by his objective truth, then the gap between the worlds in which each lives becomes even greater.

So we struck out away from sober reality and would only return after long detours. When our father wanted to go home, I'd say, "Let see what I can do for you, I think I can help." And when he asked after his mother, I pretended to believe she was still alive and reassured him that she knew about everything and was taking care of him. He liked that. He would beam back at me and nod. His beaming and nodding were the return to reality. Objective truth was often thrown under the bus. I didn't care – it was worthless. At the same time, I took more and more pleasure in letting my responses slide into fiction. There was only one standard in use: the more something soothed our father, the better.

- Geiger 2017:118

The extent to which Geiger finds it admissible to act as a hypocrite is clearly related to the effect this has on his father. If his father clearly profits from it, then it is okay, is even a must. His father is suffering from dementia, which is accompanied by a different sense of reality. Dissemblance is in this situation possibly not even dissemblance. It depends from which reality the situation is perceived: that of the caregiver, or that of the person with dementia. This is the point that Geiger is making: from the perspective of the person suffering from dementia, the objective truth can be a great dissemblance. The challenge can also be to include small aspects of objective truth in the humouring hypocrisy, through hesitations, or slightly ironic interjections or give-away comments.

This can give the person with dementia the opportunity to recall this objective reality and get a grip on it.

Hypocrisy as a way of beating around the bush

Sometimes hypocrisy is also resorted to because caregivers mistakenly assume that truth and sincerity may harm the care-receiver. Sometimes care-receivers are very much aware that the caregivers are trying to spare them in acting-as-if and experience this displayed hypocrisy as an obstacle in the care relationship. An example of the latter is found in *There Used to Be a Future* (*Vroeger was er later*), the novel mentioned in the chapter on mediocrity (see Chapter 3).

Paul, the main character in the novel *There Used to Be a Future*, finds the friendliness of the caregivers empty and hollow. He remarks scornfully that if you were born with a good humour then you have a calling as a caregiver. In his own way, he makes it clear that in his experience, the friendliness of the caregivers is the uppermost layer of indifference. For Paul however, there is nothing so visible as that which the caregivers – he calls them unrelentingly "the sisters" – are trying to hide. The following fragment makes this clear.

The sister knocks and enters the room. That's what she was taught to do: knock, not wait for an answer, just enter. Because old people (you mustn't call them that) don't hear you. Or they're asleep. Or they're pretending to be so. Or they're dead (you mustn't say that) in bed. That's what they've been taught. And that there's a lot you're not allowed to say. You can see what they're thinking. That's why I try to avoid looking at them as much as possible.

- Marynissen 2012:90 (authors' translation)

Paul would prefer not to be treated with caution. He does not want caregivers who beat around the bush. He wants real relationships with real people. What he is doing is asking for a form of respect. He wants to be considered worthwhile, as a full human person in relationship with others. The very opposite takes place in the empty polite phrases and feigned friendliness of the caregivers. They only intensify his sense of powerlessness, and he feels even more intensely what a fragile, scrawny fellow he has become.

She hangs up the shirts and shuts the wardrobe. I wonder how often I can throw the shirts out of the wardrobe and she continue to pick them up and put them away before her cheery determination (I could call it indifference) gives way to something which she hasn't been taught, something improper, something sordid, indecent, outrageous.

- Marynissen 2012:91 (authors' translation)

At the same time, Paul is aware of what is at the bottom of the hypocrisy: they want to spare him and in that way also spare themselves. The hypocrisy must conceal their impotency, namely not knowing how they can help him and what they can do for him. And if Paul is honest with himself, then neither does he know how he can help the caregivers in their powerlessness. So he plays along with the game of hypocrisy. He certainly does this with regard to his daughter.

If she asks how things are, I give the answer she wants to hear. We are two old acquaintances who bump into each other in the supermarket. One of us could burst despondently into tears. But we don't do so. We spare the other and our self.

- Marynissen 2012:201 (authors' translation)

Paul also keeps the hypocrisy going, not only toward his daughter, but also toward the caregivers. He probably has various reasons for this. In his vulnerable situation of dependency on care, it is almost impossible to say what he thinks without risk, let alone to do as he thinks. Life in the caring facility would not be bearable if he were to arouse feelings of antipathy in the people on whom he depends from day to day. This is something he has already experienced. So he keeps up appearances for the sake of peace and quiet, but also, certainly as far as his daughter is concerned, out of love. Hypocrisy is used here by both parties since both profit in a certain sense from it.

Hypocrisy as small vice in care

The various examples bring to light how hypocrisy sometimes leads to good-enough care and sometimes does not. The objective truth can be applied so heartlessly, with such complete negligence, that it wounds the other and inflicts harm. This truth is then ruthless and therefore unacceptable: a damaging truth. Hypocrisy can also harm the other, namely when care-receivers feel themselves isolated through the acting-as-if, for example the way in which Paul feels imprisoned in an unreal, false world in which everything is an appearance and through which he has the feeling that he no longer counts as a person who has a contribution to make

When does hypocrisy lead to good-enough care? This is difficult to spell out in set rules. It depends on the situation and the moment, and it depends especially on the care relationship. We need once again to recognise that complete control of care through sound rules is impossible and even destructive. The lack of sufficient procedures and rules for dealing with the (objective) truth and false appearances reveals the true identity of imperfect and fallible care that remains human.

Being true to oneself

The example of the doctor in *Summer House with Swimming Pool* demonstrates how it can be legitimate to feign friendliness, through which, in the end, you show (the beginnings of) respect, but through which you can also respect your own feelings as caregiver. Resorting to a mild type of broad hypocrisy can sometimes enable a caregiver to keep going in the care process. It is impossible, and possibly also untenable, to show each individual at all times and with complete sincerity what you are feeling or to continually give your undivided attention to the other. Fortunately there is that mild hypocrisy! It helps you to screen yourself off and to remain at an endurable distance from the other.

In this sense, mild hypocrisy helps one to remain true to oneself, namely to be true to what a caregiver wants above all to achieve. Keuter illustrates this when he admits that in some situations he acts-as-if, simply because he wants to be a good doctor to his patients. In his acting-as-if, he remains true to this goal, even if the objective truth comes off a little badly as a result. We could possibly even say that Keuter can only remain true to this goal if he acts-as-if in some situations

People who are true to themselves do not necessarily always say what they think. They do, however, always act consistently with what they think. They seek to fulfil their true intentions and do this as best they can in the given circumstances and with the knowledge that they possess at that moment. As we will see in Chapter 7, this way of being true to oneself gives expression to our responsibility for oneself.

Remaining true to what is best for the other

It is evident that it is not only when he remains faithful to his true intentions that Keuter's "acting-as-if" is acceptable, but also when these intentions are in themselves good. We mean by this: when those intentions also have the good of the other in the care relationship in mind. It is in this context that Paul experiences the gentle and always (superficially) friendly approach of the sisters as false and as a form of indifference. It does indeed appear as though the hypocrisy of the caregivers in Paul's care facility is the result of laziness. By not seeking to establish a genuine relationship with Paul, the caregivers can offer care without it demanding much of them and without specific challenges. The question can be asked as to whether this sort of hypocrisy does not impair the sincerity of the care relationship to such an extent that it is no longer possible to speak of good care. The risk of this continually feigned friendliness is that people remain superficial and do not therefore truly come into contact with the other or with how the other is feeling.

Hypocrisy is therefore not merely only acceptable when caregivers remain true to themselves, but also when they remain true to what is best for the other. Such caregivers have the other's best interests in mind, who act sincerely and without deceit, as much as they are able, as often as they must, as much as possible without this being at the expense of the other's welfare and their own. It is legitimate to act-as-if to keep going in care. However, if this pretending becomes a general attitude toward all care-seekers, becomes the caregiver's fundamental attitude, then something is wrong. Adequate transparency in one's approach is and remains essential.

The question of course is what is best for the other. Is the removal or avoidance of anxiety and agitation a good-enough reason to be hypocritical or to act-asif? Sometimes it is, sometimes not. It depends on the person concerned and their circumstances. A lot depends on the sensitivity or the attentiveness of the caregiver.

What is remarkable in the passages in which Geiger speaks of the hypocrisy in relation to his father is precisely his great attentiveness to the way in which his father continues to construct his own world, a world in which, in spite of his dementia, he still has and experiences his own identity. Perhaps it is precisely in this area that it goes wrong in Paul's case, where it seems that the caregivers possibly give too little attention to the way in which Paul constructs his own world. The want of this attention is the reason why they are insufficiently able to estimate whether or not Paul is able to have people around him who do not spare him.

Geiger's father suffers from dementia, and the hypocrisy that can prevent anxiety seems more than worthwhile. Are the anxiety and agitation that might be aroused in Paul sufficient reason for his daughter not to confront him with the real questions that preoccupy her and Paul? Everyone will agree that it is better to dissemble than to torment and better to act-as-if than to cause desperation. In the specific situations of specific people, with their specific (sometimes contradictory) emotions and (sometimes contradictory) desires, it is not however always clear what exactly the welfare of the other involves.

Acting in good faith, but in retrospect still mistakenly

Remaining faithful to the welfare of the other is, just as remaining faithful to oneself, not always so clear-cut and evident. It often demands a search, a process of trial and error, in the knowledge that caregivers at times have to backtrack to adjust the approach to the care-seeker.

An example from the novel *Care (Zorg)* by Miquel Bulnes (2012) illustrates this. The main character in the novel, a surgeon in training, is on call at the

Accident and Emergency Department when she unexpectedly meets the wife of a man who is critically ill from a tumour. The woman would like to have a word with her because she is beginning to get a bit worried. The doctor recalls the conversation, written in the third person, from her own perspective.

You say that you are not at present the physician treating her husband. It would be better to put her questions to the IC physician the following day. She is aware of this, but she would prefer to discuss it with you. Her husband felt namely that he could talk so well with you.

"Did he say that?"

"You at least were straight with him. Without beating about the bush." This is not ironic. She means it. "I'll just ask you," she said. "Do you think he's going to get better?"

You're amazed at how calm she remains while expressing these words. As though it was a rhetorical question. [...] What answer can I possibly give you? It's quarter past four in the morning. You're tired. Patients are waiting for you in Accident and Emergency. A woman whom you have seen once before wants to know something ... no ... is asking something about a patient whom you are not treating.

You don't want to answer at all. But neither do you want to lie. "We mustn't give up hope", you say. "It won't do him any good at all if we begin to despair."

She nods in agreement. "No, that's true doctor", she says. "I have to be strong. For him." She looks relieved. It worked.

- Bulnes 2012:183 (authors' translation)

In this excerpt, the doctor decides, in the given circumstances and with the knowledge she possess at that moment, to pretend and act-as-if. She chooses not to unreservedly reveal the truth. She has just had a demanding night in Accident and Emergency. A lot has happened, and she is exhausted. She feels that this is not the right moment for herself to have this conversation with this woman. At the same time the woman is standing in front of her with her question. And she feels the woman is putting her trust in her, a trust that she does not want to betray. She also senses – or judges – that the woman does want a sincere answer, but that she is not yet ready for that answer. It is a judgement of that moment. Possibly, when she has recovered her energy, she may come to the conclusion that it was a mistaken judgement. Possibly, later on, when she has to give the lady bad news about her husband, she may feel that she has lost the trust the lady had placed in her. But maybe not. Whatever the case, at the moment in question, the doctor acted in good faith, namely in the knowledge that she possessed at and in the context of that moment.

Acting in good faith is to act genuinely. It is remaining true to yourself and in the best interests of the other, as much as possible, as much as is necessary, and taking the context and knowledge at that moment into account. It may become apparent from a subsequent team meeting or conversation that it would have been better to be completely sincere and transparent. It may even happen that caregivers are of the opinion that one has acted incorrectly. Nonetheless what was done was good, because it was done in good faith.

The reverse is of course also possible. Geiger makes it clear that hypocrisy in relation to his father did not feel good at the time, and that he only later came to the conclusion that what was done at that time was good. Only later did he come to the full insight that even the objective truth can be very hypocritical. And that good-enough care sometimes turns things upside down. That is the paradox of good-enough care as a learning process. Acting in an ethically correct way is never a fully acquired insight. This is precisely what gives caregivers breathing space, for it is through doing that they learn what good-enough care is; this guards them from becoming fraught and cynical. Often the intention of caregivers – the intention to truly do what is best for the other – runs into trouble in real life. This brings about a tension that can only remain bearable and human through the necessary creativity and humour.

Care incentives

The following questions and activities can guide the caregiver in dealing with hypocrisy:

- Think of two patients/clients/residents, one person with whom you have good contact and another person with whom the contact is not so easy. Consider with which person you are the most open. Do you notice a difference in terms of hypocrisy in relation to the first and to the second? Talk about this with a colleague.
- 2. In which circumstances does "honesty is the best policy" not work for you?
- 3. When does wanting to spare someone get you into a mess with yourself or with colleagues?
- 4. Are there situations you can think of in which you would never say the objective truth?
- 5. How do you, together with your colleagues, keep up a type of broad hypocrisy? Are there people who you suspect suffer from this?
- 6. What do you prefer yourself, that you are spared, or that someone carefully but clearly explains the real prognosis to the other?

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"Acting in good faith is to act genuinely. It is remaining true to yourself and in the best interests of the other, as much as possible, as much as is necessary, and taking the context and knowledge at that moment into account."



"I SOMETIMES SAY EXACTLY WHAT I AM THINKING"

ANGER: KEEPING COMMITTED CARE
ON THE BOIL

Miquel Bulnes (2012), in his novel *Care* (*Zorg*), tells the story of the life of a young surgeon in training. She gets to know life in a hospital the way it really is. Besides the dissembling relations with patients and their families, she also comes across the peremptory rules of a strongly hierarchically structured system. She unwillingly plays her role in this context. And yet, in some situations, she pertinently refuses to be (completely) silent about how she actually thinks or feels, both toward a (senior) doctor and toward a (an outspoken) patient. The following fragment, in which the main character has to call up the surgeon on night duty during an emergency situation testifies to this. He flatly refuses to come at once. He snaps at the main character: "Do you have any idea what time it is?" He says he will only come after the most senior auxiliary has assessed the situation and calls him up. A quarter of an hour later, the most senior auxiliary has not yet turned up. The ambulance has arrived and the patient is in a very critical condition. The main character calls the senior surgeon once again.

You again? he asks. Are you aware of the time?

"Yes", you snarl, "I am perfectly aware of the time. I have my own watch, so I have no need to call you for that information. A critically injured person is lying here in Emergency, so instead of asking stupid questions, you need to get dressed and come here immediately. You should have been here ten minutes ago."

She hangs up.

- Bulnes 2012:122 (authors' translation)

Some hours later, when the state of the critical patient has just become stable, the main character is called up by Accident and Emergency. Another patient is apparently waiting for her there. She goes to have a look and a man is sitting there.

The gentleman is not happy. The gentleman is angry. He has been waiting for some time. You are aware of this. Some three hours or so.

After all, you don't let someone wait that long, not in the middle of the night! The gentleman has something better to do.

The gentleman has a painful ankle. It is now time to examine this painful ankle. And sharp!

You ask how long the ankle has been painful.

Since Sunday evening.

Since Sunday evening?

Yes, since Sunday evening.

So the gentleman has had a painful ankle for four days?

That is what I just said, says the gentleman.

Does the gentleman realise where he is at present?

What a stupid question, of course he knows where he is. He is at present in the Accident and Emergency hospital department.

Could the gentleman then perhaps clarify at which exact moment during the past four days the pain in the ankle became urgent? The gentleman becomes even angrier. He has no time for this sort of game. He will just go to another hospital. There are more hospitals in the area.

You almost say: True, but they may not have any room for you in those other hospitals. This is the only hospital in the region in which there is still room for patients in intensive care. But instead, you say: That's quite true.

The gentleman stamps away.

You almost say: Watch out for your ankle!

- Bulnes 2012:139 (authors' translation)

These two excerpts break through the acting-as-if. There is no question here of the acting of which Keuter speaks at the beginning of the previous chapter (Chapter 4). The main character speaks out forcefully even if she is still in training and on the very last rung of the hierarchy. She gives vent to her irritation or anger in these excerpts. Amiability and perhaps even basic courtesy are absent. Is this acceptable? Is it permissible? In the first excerpt, where a firm line is taken with the senior surgeon, he comes and does what may be expected of him. In the second excerpt, through the main character's anger, the patient's own responsibility and decision are pointed out to him.

Where the last chapter involved a plea for a certain hypocrisy for the sake of good care, in this chapter we point out the role of anger or visible irritation in the care relationship. Should the other, the caregiver or the care-seeker, always be spared? When should this not be the case? When may it even absolutely not be the case? Or to put it more generally: when does anger lead to better care?

Anger in caregiving as reaction to having been wronged

Many caregivers feel a rising inner resistance at the first mention of the word anger. The word brings to their minds scenes of extreme violence. They also resist feelings of anger because, they ask, how can violence be consistent with professional or good care? However, the anger of the main character in the novel can hardly be said to be a form of violence. Anger involves a broad range of emotions that are on the continuum between fury at the one extreme

and irritation at the other. This can go from blind rage and fierce outbursts of anger, through acid bitterness, to irritation and annoyance expressed in a curt response or an angry manner of conduct. In the novel, the young doctor in training does not foam with rage. She may possibly be seething with anger within, and her anger toward the senior surgeon is outwardly expressed in a message that is not to be misunderstood. Her anger toward the patient comes to expression in an ironic sort of way.

In both passages from the novel, it is evident that it is the conduct of the senior surgeon in the one case and that of the patient in the other that arouse the main character's anger. However much caregivers resist feelings of anger, such feelings exist in situations where people live and work together. Sometimes one person does something that elicits the anger of the other. In human relationships, anger – in whatever form – is often a reaction to being wronged. Wrong here relates to something done to me by the other with which I do not agree or which I find unacceptable. The reaction is also independent of whether the wrong has been inflicted consciously or unconsciously.

Anger because you have not been acknowledged

The ethicist Annelies van Heijst (2008) explains in her book *Being Aware of the Other (lemand zien staan*) how care very basically has to create a dynamic of acknowledgement between people. One can only speak of good-enough care if partners in the care relationship acknowledge each other, as a human beings and as a person. It seems initially that the main character's anger in the novel is related to this criterion of acknowledgement: she does not feel acknowledged, neither by the senior surgeon, nor by the patient. The senior surgeon makes her feel in no uncertain terms that she is inferior, she is merely a doctor in training who does not have the competence to be able to determine when to appeal to a superior. The patient in the second excerpt seems to think that care-providers in Accident and Emergency are idling around, waiting for patients; a doctor is reduced to being simply a sort of (in this case poorly performing) service provider.

Anger is not infrequently the reaction of one person in the care relationship to feelings of not being acknowledged in and through the conduct of the other. Paul, the main character in the novel *There Used to Be a Future (Vroeger was er later)* by Marynissen (2012), responds with anger as care-seeker to care in which he does not feel acknowledged. The caregivers do not seem to be aware of having done any wrong, but at one point their indifferent and patronising way of providing care makes Paul furious. When a new caregiver observes one morning that he is already out of bed, his reaction is one of anger; she points

out to him that the earlier he gets up, the longer he will have to wait to be washed.

I know! I shout. As if I had not used my voice for some time.

I haven't used my voice for some time. Shouting, singing, crying out loud – none of it is permitted here.

Well-bred people (elderly people in a nursing home) do not behave in that way. Standing opposite that child at the washbasin at this moment, I can barely restrain myself from more furious yelling, swearing and passionate rage. It would make me feel better, completely empty and clean from within. It is not permitted. I clench my fists; I bite my tongue. There is saliva on my lips.

- Marynissen 2012:45 (authors' translation)

The caregiver in this situation does not know what is happening. She is taken by surprise by Paul's anger. He is reacting not so much to her words as to his situation of dependence on care and the suffering, in which he, in the total provision of care, does not feel sufficiently acknowledged. The caregiver does not realise however that Paul's anger is a reaction to the wrong that he has suffered (and of which she is just a drop in the ocean). She cannot perceive that the man has a very deep invisible wound that is wrenching his soul. Neither does she attempt to speak to him, she poses no questions. She does go and get the senior nurse, who tells Paul off in a patronising way for his unacceptable behaviour in the presence of his daughter ... And the doctor is asked to prescribe a tranquillizer.

Anger as response to threat or danger

Before exploring the lack of acknowledgement of anger as a response to a suffered wrong – and the pernicious effects of this for care – it is important to first consider anger as a reaction to a suffered wrong. It seems clear that the anger of the doctor in training toward the surgeon is not only a reaction to his behaviour, which communicates a lack of respect, but is also a reaction to the fact that the man does not seem to realise that a person's life is at risk. The doctor in training's anger is thus a response to danger: what provokes her ire is the fact that the senior surgeon arrogantly leaves her in the lurch with a patient who has a life-threatening injury. Here her anger results in a reaction to salvage what can be salvaged and there is no time to lose in the process.

Anger is often a reaction to a dangerous situation. The aroused wave of anger gives the person in danger the necessary information as it were to grasp what has to be done, or to clarify "what do I want?" and "what is needed to avoid this danger?"

In caregiving people very often feel uncertain because the situation is unfamiliar to them. As a result, they often respond in anger – sometimes even in an aggressive way – because they may not know how best to react to a situation. This uncertainty may be due to their physical or mental state or simply their fear of the unknown. Geiger, in his book *The Old King in His Exile* recounts how his father lashes out at him in anger. His father has refused to allow himself to be washed by the caregiver and has locked himself in the bathroom. Geiger reacts to this. He writes:

I begged repeatedly before my father opened the door. He was sitting on the bathroom stool in his pants and a white undershirt, his skin hanging slackly from his arms. The two towels around his neck were knotted together on his chest, and in one hand he held up a long-handled back scrubber, and in the other, nail clippers with the file flicked out. He did look like a king now, with a scepter and sword.

- Geiger 2017:105

Geiger notices that his father is hallucinating. His father looks toward the shower and asks what he should do with "the others". Geiger reacts:

Instead of calming him down by letting him know I'd protect him and chase off "the others", I tried to divert his attention – in vain. He still felt threatened. With his head hunched over, he kept darting glances left and right, alert to any dangers.

- Geiger 2017:105

Then, because Geiger himself feels threatened, he becomes furious. He writes:

When I tried to take the scrubber from his hand, he made as if to hit me. I jumped back in surprise and then gave him an earful, shouting, "Are you crazy? You're a pillar of the community – and that's how you behave?! Who taught you that? Certainly not your mother! And you never taught us, your children, to do anything of the sort!

- Geiger 2017:106

Only later on does he find a possible explanation for his father's behaviour in the realisation that his father possibly thought that he was in a Russian army camp where he had been imprisoned for several years after the war. The fact that the Serbian caregiver spoke broken German and was controlling towards him had perhaps contributed to this.

Anger as moral indignation

Geiger demonstrates by his example that anger as response to danger or being threatened is not characteristic only of people with dementia. He flares up in anger when physically threatened by his father. A situation does not even need to be physically threatening to provoke anger. The doctor in training responds with unconcealed irritation the moment that she is confronted with the verbal attack of the patient with the painful ankle. Yet there does seem to be more involved here. Possibly her anger also indicates a certain indignation. After her experience earlier that evening at Accident and Emergency, we may conjecture that it infuriated her that someone who is not in such a bad way can be so demanding. In the situation of the patient who almost lost his/her life because the senior surgeon initially refused to attend, the anger is an indignant response to a person's display of power, to putting another person's life at risk.

Some situations in caregiving arouse moral indignation. These situations make caregivers angry. This is not because they have not slept well, because they are irritable or because they have a bad character. It is because they become outraged by the injustice that other vulnerable people have to endure, or by the wrong that one person does to another. Anger reveals itself here as a form of moral resistance. Other than physical resistance as discussed in the chapter on antipathy (see Chapter 3), the resistance toward the other is aroused here by a form of injustice perpetrated by this person. The moral resistance that people feel toward others is thus related to their - extremely negative - judgement about the behaviour of those people. Moral indignation is often rooted in a negative contrast experience, namely the experience that causes a person to call out: "This has to stop!" "This is unacceptable!" "This can't go on this way!" Moral indignation is thus anything but a neutral feeling. It is a complaint that hits the person undergoing the contrast experience smack in the face. This causes the person to take a position, to make a judgement or even express condemnation, or to burst out in a sort of sacred anger.

Moral indignation has many different facets. Sometimes this sort of anger is directed at specific others, as a result of their behaviour, but it can also be directed at organisations and at injustices that occur through the care system itself. This sort of moral indignation – directed at organisations and systems – is the subject of the following chapter, which is about disobedience. In this chapter on anger, the focus is on moral resistance as a reaction to the behaviour of a specific person.

What happens when anger is concealed?

Anger as an expression of moral indignation is a sort of ethical energy, namely the energy to denounce injustice or lack of respect. Anger can however have a self-directed aspect to it, namely when it is a reaction to being threatened or to not being acknowledged. In this case, anger is an emotion of the soul, namely an expression of a healthy instinct for self-preservation. Anger helps to guard one's own boundaries in relation to the other and to defend oneself. It is a way to stake out one's own boundaries and make oneself safe. Anger can contribute to the self-awareness of caregivers and to their own sense of worth. According to Lytta Basset (2002), in this sense anger is a life force. It is a life force that expresses that we are involved both with the other and with ourselves.

Yet anger toward the other and love for the other are often considered as being incompatible. Good care would then mean that you cannot have any conflicts, that it is unacceptable to feel anger, let alone express it. The stand-up comedian Wouter Deprez says of this in an interview:

It was unacceptable. At home, and in the region I come from, emotions in general were not so acceptable because they can make you unbalanced. Ugly feelings such as jealousy and extreme rage were fundamentally wrong. If you hear often enough that something is not allowed, you begin to suppress such feelings, until you don't even notice them anymore: you have to be immaculate, a sort of saintly figure. Your neighbour may have such feelings, but you don't, do you? And that neighbour of yours, you certainly condemn him very strongly for those ugly feelings that you know nothing about.

- Wouter Deprez 2012:26-31 (authors' translation)

Anger can of course be damaging to caregiving. Damage occurs when anger expresses itself in verbal or physical forms of brutality or rudeness, sullen indifference or tormenting, or forms of bullying, cruelty or terror. This damage, though, is more of a risk when feelings of anger are camouflaged or suppressed.

The care relationship turns sour

Defining anger not as blind hate or strong resentment but rather as a reaction to a suffered wrong, clearly illustrates why Basset (2002) identifies anger as a life force: without anger, people have no defence against threatening forces which they face. Through Sigmund Freud we learned how the suppression of spontaneous energy, urges and natural tendencies such as anger leads to repression. Emotional energy such as anger cannot just be suppressed; and if that anger is repressed, then it will come to expression in another,

possibly defected, way that will turn everything sour. A caregiver who has been embarrassed by an outspoken patient will vent her anger on others, for example colleagues, family members or less outspoken caregivers. This sort of collective anger often leads to a gossiping and backbiting culture that is not expressed but continues to live on in a repressed fashion and taints everything.

People show through their anger that they have been hurt. They show that they have suffered wrong. This is why it is of the utmost importance to accept anger: it is the sign that one has been hurt. If people do not make room for their anger, then it continues to live on in a repressed manner and in this way receives every opportunity to develop into resentment and vengeful feelings or into fits of anger during which people lose all self-control. If the anger is not identified as such then it is submerged and given every opportunity to cause irritation subconsciously. In this sense, anger is the first step toward exercising a certain control.

The care relationship becomes more reserved

Anger is as already mentioned an ethical energy: it gives people the strength to point out injustice or want of respect. Anger demonstrates people's involvement in caregiving. This is the complete opposite of indifference. It is in any case clear that something happens to people when they suppress "energy to change": they become indifferent and cool. This may not happen consciously, but their refusal to be no longer involved in very real.

In very specific care relationships, something happens at the very moment that emotions such as anger are suppressed or brushed aside. People do not give others any indication that they have been hurt by them. This means that they keep up appearances toward others. How the continual keeping up of appearances affects care relationships has been sketched in the previous chapter: the authenticity of a care relationship is destroyed when hypocrisy is continually present. This is true of course for every relationship and applies also to friendship and love relationships. Wouter Deprez comments:

It would be better if we were rigorously truthful with each other. We should be very generous in telling our friends what we like and do not like about them. But rather we say good-day to them, and they say good-day to us. If we are really stuck, we must immediately visit a specialist, go to someone who has studied whatever the problem is. One would like to hope that by this time we were so well-advanced in our emotional development that we would have some experience with the problem, that we would know how to untangle ourselves. Or that we could at least accept that things are not

going so well for the other or yourself. But no, that's not allowed either: it is a sad affair.

- Deprez 2012:27 (authors' translation)

Good care is not possible without taking a person's experience seriously, precisely because that experience is intrinsic to a person's self-respect and self-confidence. Every person, both caregiver and care-receiver, has the need to be acknowledged and heard as a specific person. Respect is given at this fundamental level in and through being taken seriously in what one is feeling. This is also true when it comes to anger. People demonstrate respect for each other by acknowledging the other's anger and by identifying one's own anger toward the other. Asking the question, "Am I correct in thinking you are angry?", is an expression of compassion and a form of acknowledgement. Possibly this question would have been an important step in the care process for the nurse who received the full force of Paul's unjustly expressed pent-up rage ... (see Marynissen 2012).

Anger as small vice in caregiving

Bottled-up anger leads to resentment and feelings of hate which may then explode at people who are unable to do anything to help and who are often not even able to defend themselves. Only when we suppress anger do we give it the opportunity to possess us and to degenerate in this way into something violent. It is therefore clear how important it is to express one's anger and preferably toward the right person at the right moment. And yet anger is not in this way a lever for good-enough care. That is only possible if anger is also expressed in the right degree, at the right moment, with the right intention and in the right way.

Expressing anger to prevent wrong or to avert danger

There is always the tendency with anger, as a sort of natural reflex to suffering a wrong, to hit back and to take revenge. According to Rota (2007), the influential medieval philosopher Thomas Aquinas recognised this. For Aquinas, anger (*ira*) is the desire to hurt the other with the intention of repaying in a similar way, the damage caused. Some sort of urge for retaliation flows out of the spontaneous anger as a reaction to a suffered wrong. The person who has suffered the wrong wants to give the other a taste of their own medicine. The perpetrator can in this way experience the effect that the wrong suffered – insults, gossip, contempt, abuse of trust – has had on the victim.

The risk of disproportionality is always present in the emotional urge for retaliation or satisfaction (with the chance of further escalation). Anger is then expressed, but it only leads to further violence in the care relationship. This is why it is important to become aware of one's own anger and the longing for retaliation. It is only on the basis of this awareness that the conscious choice can be made not to take revenge. The risk of revenge is certainly relevant in the context of caregiving. Care relationships are unequal and often the caregiver, from his/her position as well as his/her expertise, has a certain power over the care-receiver. This is certainly true when the latter is very vulnerable and powerless and therefore dependent on care. Some cases of elder abuse are an expression of the retaliation of children, as soon as that parent has become vulnerable and powerless, for a parent's many years of tyrannical behaviour, and sometimes verbal and physical brutality can be a way of making a dependant elderly person who does not cooperate or who is continually resistant, pay for this behaviour.

The retaliation of the doctor in the two novel extracts does not seem disproportionate. The patient is not vulnerable to the extent that he/she has been abandoned to his/her fate. The doctor's urge for revenge expresses itself rather in some sort of irony that confronts the man with the part he/she has played in the situation. In the situation with the senior surgeon, the trainee doctor's urge for retaliation expresses itself in a demand for rectification. The expression of her irritation halts at the very least the senior surgeon's abuse of power. The young doctor makes it clear to her superior that a person's life is at stake.

Caregivers can suffer wrong from vulnerable care-seekers, without the latter being aware of this. This is for example the case with people who are suffering from dementia. Is anger acceptable in this case? Even if a victim refrains from retaliating and if the anger is intended to bring the wrong to a stop, there is still a risk in such situations of an escalation of anger. Much depends of course on the way in which anger is expressed toward these people. We referred previously to Geiger's anger toward his father who had locked himself in the bathroom after having threatened the caregiver. He recalls how he initially controlled himself, but then let himself go in his anger after all. Geiger writes:

I really let it rip, mentioning all the things that would cut him to the quick. Interestingly, the lecture had an effect. He looked disconcerted, as if he were ashamed. Of his own initiative, he put down the scrubber and agreed when I said I was going to take the file. Now the worst was over. I helped him on with his shirt and steered him to the television. He appeared relaxed, exaggeratedly cheerful, and ready to joke around. Meanwhile, Maria was

crying in her room? She had struggled with him for an hour and let him threaten her with the scrubber many times.

- Geiger 2017:106

Geiger's anger comes to expression in a purposeful and frank articulation that is not without effect. Although he is affected by the aggression of his father – he is ultimately physically threatened by the "old king" – the anger does not degenerate into verbal counter aggression. The aggressive behaviour of his father stops.

Anger as a form of rectification

In relation to Geiger's anger, the urge for retaliation or rectification of which Thomas Aquinas speaks is channelled into action that is intended to make his father's threatening aggression stop. That is not only a very legitimate but also a very necessary form of rectification. The way in which Geiger approaches rectification is reasonable: he appeals to reasonable arguments to calm his father. He succeeds in dealing with the angry feelings that his father's behaviour has aroused in him with a certain reasonableness. By reflecting afterwards on the possible causes of his father's behaviour, he prepares himself for the next threatening situation and also for how he could respond better to it.

Expressed in the anger is the legitimate and reasonable demand for rectification, settlement and justice. The rectification means in the first place stopping the injustice, insult or wrong. This is an important and legitimate function of anger in caregiving. People who suffer a wrong, who are not respected, who are belittled, who are even physically or verbally threatened, do not need to accept this. This also applies to caregiving. It is both very human and responsible that these people do something to stop the behaviour of the other. In some situations, a formal rectification is necessary, for example through an apology from the perpetrator. If there is no rectification at all, then people are violated in their sense of self-respect and self-worth. The rectification intrinsic to and present in anger therefore has an important place in caregiving.

The way in which the rectification takes place of course also plays an important role. Anger only leads to better, more balanced and just care relationships when it is channelled in the right way. In this respect, it would be irresponsible to let the expression and actualisation of the longing for rectification depend on the emotion itself. If this happens, then one may speak of a temper derailment that can lead to a further escalation of aggression, revenge and counter-revenge. At that moment, anger loses its initial ethical character. A certain reasonableness therefore needs to be applied.

Anger that rouses the other to responsibility

Moral anger does not therefore guarantee the ethical quality of the care relationship. Indignation can be unfounded. A caregiver can be angry about the behaviour of a colleague, while it later becomes apparent that this behaviour was not so reprehensible. Moral anger remains therefore a non-rational form of judgement or condemnation. It can be an expression of preconceptions or blind spots or even worse: it can be an expression of moral pretentiousness. In a column on moral indignation the philosopher Tinneke Beeckman says:

Whoever raves about indignation can easily be hiding behind a mask of fairness. Whoever calls on indignation from a self-evaluated sense of moral superiority wants above all to put himself in the picture. [...] This lonely protector of moral principles is usually full of resentment and harbours frustration and feelings of revenge. [...] Indignation is an immediate feeling, an outpouring of the heart, not an admonishing finger.

- Beeckman 2013:39 (authors' translation)

Only when anger is in line with reason does it become reasonable. The testing begins when caregivers begin to discuss anger with one another. This demands courage, however: the moment a person acknowledges his/her anger, that person becomes vulnerable. What is important is that anger is restrained. A small anger that has been tempered and reduced to the right proportions can be an expression of responsibility and even of caring.

Geiger's response reflects such a small anger. The reaction of the trainee doctor from the novel *Care* also reflects this: her anger makes an impact precisely because she becomes angry in a reasonable way. It makes its impact on the senior surgeon who stops his abuse of power and takes up his responsibility. In the case of the patient in Accident and Emergency, the man is halted in his disparaging attitude. The doctor does not allow him to continue to belittle her and reduce her to an object.

In brief, anger can come to the surface as a healthy psychological reality and can moreover fulfil an ethical role in bringing about better care, on the condition that such anger is expressed in the right way and toward the right person. This is not within everyone's capacities and is also not easy, precisely because it concerns an emotion that is initially irrational and which, because it is so passionate, does not necessarily submit itself to reason. The small anger demands the wisdom of experience. And as this phrase itself indicates, the wisdom of experience means that such wisdom is not available beforehand, but develops through trial and error in the course of practice, self-knowledge and exchange.

The recognition, exploration and communication of anger in as honest and open a way as possible is a form of vulnerability that is not so self-evident. It demands courage and humility. It is by the way much easier to minimise one's irritation: "It's not a problem" – "Doesn't bother me!" – "I can deal with it!". In this way you can avoid the confrontation with it. In this way you don't have to put your energy into looking for the reasons for your anger, to talk out the conflict or to do something. You don't then run the risk of the escalation of the conflict. The conflict can however fester. In such cases the risk exists of silent violence and pain and wounds that receive no chance to heal.

Fortunately, caregivers are not inviolable or feelingless spirits that are superior to all things. They can and may feel anger. Anger demonstrates that caregivers can be sensitive and can be touched and are certainly not indifferent to forms of wrong suffered: insults, injustice, humiliation, unfair treatment, abuse of power, broken trust, indifference, and so on; all matters which undermine good-enough care. Anger functions as an alarm bell or a warning light. It indicates which of a caregiver's sensitive spots can be touched or threatened, or where they have the feeling they are being imposed on. In contrast with caregivers who hold in their anger and hide behind an attitude of indifference or resignation, through communicating in an appropriate - sensible and controlled - way, caregivers can indicate that they are concerned with what is good, namely the welfare of their care-receivers. Anger also gives them a lever with which to work at giving better care. It can even bring caregivers to a form of refusal or reticence, a form of disobedience toward care-receivers who make inordinate or even harmful care demands. It keeps them alert and critical and from not just acquiescing to a well-intended compassion with all that care-receivers feel is necessary for their health and welfare

If anger gets stuck in the negative contrast experience where one can speak of moral reluctance, then it acquires a negative character. This is why it is better, both for the person providing the care and for the one receiving it, to transform it into a meaningful experience that leads to good care. The "small goodness" (Levinas 1995:119) mentioned earlier in this book (see page 51) offers such a meaningful experience. It is true that it concerns a small, fleeting moment, and yet it is precisely in such small goodness that caregivers experience the significance of their care. It is the opposite of the negative contrast experience: "This is it!" – "Now it is clear!" – "Now I am convinced!" It is the small anger that sometimes makes this meaningful experience of small goodness possible.

Care incentives

The following questions and activities can guide the caregiver in dealing with anger:

- 1. When do you feel roused to anger in your contact with the other? What prompts you to express that anger?
- 2. What do you see as an acceptable way of expressing your irritation and aggression? Do you do that impulsively, after a brief time-out or after having given it some thought?
- 3. Do you feel acknowledged in your work? When do you feel that the value of your work and effort is being overlooked, and does this give you a feeling of being aggrieved or make you angry?
- 4. Sometimes it is necessary to stop the behaviour of the other. How do you do that? Do you bring it up again later on?
- 5. Behind anger there is a wounded soul. Do you dare to ask questions of someone about why they are angry? If you would like to learn to do so, what first step can you take now?
- 6. Do you see anger as something constructive? Do your relationships with clients and colleagues benefit from it? When is this the case and when is it not?

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"Caregivers can suffer wrong from vulnerable care-seekers, without the latter being aware of this."



CHAPTER 6

"I AM NOT DOING IT THIS WAY ANY LONGER"

DISOBEDIENCE AS A 'VIRTUOUS VICE'

It seems like a detail, yet it is more than that. The trainee nurse who makes an appearance in Paul's room does not wear the same uniform as the other caregivers in the residential home. We mentioned her earlier in the chapter on mediocrity: Marieke (see Chapter 3). She makes a brief appearance in the novel *There Used to Be a Future (Vroeger was er later)*; she flutters like a butterfly into Paul's life. Initially, Paul isn't sure what is happening when she comes into his room.

"Hello", she says.

I'm not sure if I should say anything. She's wearing the same uniform. She wears it in a different way. I'm not sure exactly how. She knows all right: she's made changes to her uniform.

"Re-sewn!" she says.

Tore open the seams, cut bits away, tried it on, measured it, sewed everything back together again. Easy. She shows me where she has taken it in and by how much.

She draws lines from her one arm to her other arm, from her armpit to her bottom. She turns around, lifts up the jacket a little, and shows how she has taken in the waist of the trousers. Tells me that this is really not permitted. 'A uniform is a uniform' the matron had said. A pocket is a pocket. I still haven't said anything, only looked on. Speaking is silver; looking is gold.

She goes and sits on the windowsill. She's wearing white trainers. And socks that come to just above her ankles – I didn't know they existed.

- Marynissen 2012:121 (authors' translation)

Her appearance. Her way of entering the room. The way in which she makes contact before she goes about her work. Or rather, the fact that she doesn't immediately go to work, but first goes and sits on the windowsill to have a chat. It's different. Marieke, the trainee nurse, does not behave in the way one would expect in a retirement home. And she dismisses the rules on wearing a uniform. This is unusual behaviour for a trainee nurse. Her contrary ways do not always go down well with the matron, she says. They couldn't be better for Paul. Her unusual way of behaving is a breath of fresh air for him: at last, someone who treats him like a normal human being. At last, someone who doesn't cling to the series of prescribed (care) activities.

Does Marieke's behaviour fall under the category of disobedience? What is disobedience in healthcare? What significance does it have for healthcare? When could it be helpful and responsible?

Disobedience in healthcare

Type in disobedience as a search term and Google takes us a long way from the mischievous Marieke. The serious concept of civil disobedience comes to mind, where citizens purposely break the law or ignore the rules because, in their opinion, the rules are unjust or discriminatory. They thus step deliberately outside of the law. They consciously think outside the box. They knowingly act illegally and risk being punished. They do this to communicate publically their dissatisfaction with the system, which in their opinion is flawed. All other attempted methods to publicise their opinion have had no result. This is the reason for their public act of disobedience. The disobedient civilians make a statement in this way and give the public a wake-up call. Sometimes the punishment that they receive as a result of their disobedient behaviour is precisely the statement that they want to make.

The same Internet search highlights another form of civil disobedience. Max A. Huber (*Stichting Eropaf!* [Go-for-it! Foundation], the Netherlands) speaks in a presentation of professional disobedience (Huber 2013). This form of disobedience arises in organisations where caregivers experience fundamental displeasure in relation to the way in which care is organised and managed. They experience that the rules that are applicable in their section or within the whole organisation are in contention with what they feel constitutes good care. This is why they consciously and deliberately disregard the rules. At the very least, they demonstrate that they are not in agreement with the system and that they distance themselves from the way in which healthcare is organised. They especially refuse to let themselves be seen as people who carry out the work of such a healthcare organisation.

The analogy with civil disobedience is clear: caregivers are disobedient to the regulations because these conflict with what they see as caring professional action. They do not automatically accept the policy in such a situation because this policy conflicts with their ethical concern. Professional disobedience thus concerns everything that caregivers do in order to demonstrate openly that they cannot reconcile themselves to what is expected and demanded of them. According to Huber – who here quotes the vice-president of the Dutch Council of State – caregivers then need to say: "We are terribly sorry, but we are not going to do it this way anymore." When this happens, disobedience functions as a sort of crowbar that creates the space for a more professional way of doing things. Caregivers should continue their disobedience until the system itself changes, says Huber. This means: until professional ethical activity is no longer disobedience.

Disobedience on the basis of moral indignation

If we explore the concept of professional disobedience more extensively, then a first characteristic stands out: it is a form of disobedience that arises from the caregivers' dissatisfaction with the organisation. The caregivers are indignant. The indignation that they feel is a form of moral resistance. The indignation is related to the structures and the structural wrong, namely, the wrong that is created within the structures of an organisation and through which it is precisely those people who require care, who are left in the lurch. People are vulnerable as a result of their dependence on care and as a result run a greater risk of suffering through the care system. When these people suffer, it cuts the caregivers to the quick. When all sorts of rules, procedures and protocols become, in their minds, obstacles to good care, they become angry with the system or with the way of working in their care organisation. They find such matters incredibly lacking in compassion and even perverse.

The attitude of their colleagues, who see themselves as the executors of the professional and well-oiled care system and ignore the ethical protest to the way care-receivers are being treated as a result of the care system, also arouses their anger.

A nurse writes a letter¹ to the senior nurses and doctors of a department where she does not work herself, but where she has witnessed something that has made her indignant. Her indignation is related to a needy, fragile, elderly woman who shared a room with her (the nurse's) aunt. She writes in her letter of this woman:

She was French-speaking and in the first few days explained that she was alone and without children, that she still had one sister who lived quite far away, that she had already been in hospital for four weeks and that she felt she was getting worse every day. She knew I was a nurse because I was sometimes wearing my uniform when I visited my aunt.

The nurse subsequently describes a number of "small" matters that happened during the time that she was visiting her aunt and therefore also being in contact with the person sharing her room, the French-speaking woman.

On the Saturday she said to me that she wanted to go to the toilet and would ring for assistance in this ... but asked if I would be prepared to help the nurse who answered the bell to help her onto the toilet seat. "I can hardly stand on my legs anymore and yet they do it alone and it's too painful for me", she said. I said I would help her. The nurse who answered

This letter is based on a real incident and is presented in such a way that the anonymity of the nurse is protected.

VULNERABLE RESPONSIBILITY

the bell said however that she would do it alone and that the lady was too anxious. So I held back. I heard the lady moaning and finally the nurse called to ask if I could help as the lady's legs would not hold her.

The lady feels that she is getting worse and worse, does not understand what is happening to her, and there is nobody who will offer her any explanation. The nurse writes in her letter of how she has advised the lady to ask her doctor and her nurse openly for more information about her condition. A few days later, something happens that the nurse also describes in her letter:

When I visited my aunt on Wednesday evening, the nurse was just leaving the room when I arrived. I think that she had just put out sandwiches for the lady because a tray was on her bedside table. The lady lay in an uncomfortable position; she had slid down and was caught up in the lines of her drip. I thought that the nurse had possibly gone to seek help to get the lady back into a better position, but no-one came back. I asked if I could help her to eat, but she said she didn't want anything to eat. "I think I'm going to die. I feel it in the pain in my stomach." I tried to unravel the lines and saw that she now had a central catheter. The sheets were covered in blood from one of many open sores. The under-sheet was also doubled up. I found a nurse in the corridor who was prepared to help me in spite of her busy schedule to get the lady into a better position. [...] A little later, when the nurse had left, the lady said to me: "Miss, I'm going to die and there is no-one who will listen to me." She pleaded with me to phone her sister. I hesitated to call a nurse again as they were very busy and I did not want to interfere. To my relief the telephone began to ring. It was the lady's sister. She cried of distress. "I'm going to die". [...] The next day I went to visit my aunt and she had a new roommate. On leaving, I asked a nurse about the lady. She said: "She died; it happened very unexpectedly."

These last words especially were the proverbial last straw, for it was hard not to see or hear the lady's cry of distress. And yet that is what had happened ...

The nurse's indignation is not only anger, but also disappointment and sorrow. She is sad about what has happened to the old lady. She cannot forget the woman's unheard cry of distress. Just as she cannot forget that the woman had died in the greatest imaginable loneliness. This death touches her deeply, and her ethical sensibilities are offended. The philosopher Levinas speaks of this:

I think that the fear for the death of the other is at the basis of our responsibility for that other. Does the naked look and the miserable body of the other not point to the most extreme exposure, namely exposure to death? The experience of the call to remain close and stand by the person

comes from this, above all, to not leave the other alone, certainly not in the face of the most inevitable: death.

- Levinas 1982:128 (authors' translation)

This implies a new ethical imperative for Levinas: "You will not leave any person to die alone". He is of course aware that every person is lonely in death. No one of us can accompany another in that last moment. He is also aware that death often comes like a thief in the night: however hard we try to be there, it can still outwit us ... just at that one moment that we are not able to be present. With his statement: "You will not leave any person to die alone", Levinas means that we must not leave the dying other to his/her fate, even if there is nothing that we can do and can only hold the person's hand.

This new ethical imperative also relates to the organisation of the care. It should be organised in such a way that people do not have to die alone or completely abandoned. Failing to provide such an ethical care culture is precisely what has aroused the indignation of the nurse and what has caused her to take up her pen. She concludes her letter:

I do not mean this to be a letter of complaint, and I hope that nobody feels hurt. There are many things I do not know. I do not know the reasons for hospitalisation or for the diagnosis or therapy. What I saw, as a visitor, was a fragile, elderly, person who was alone and extremely in need of care. She had no-one to stick up for her. It may well be that from a medical perspective her death was not to be directly expected, but was that also the case from a humanly compassionate point of view? Is it not precisely in this area that we have an important task as caregivers? In whatever position or role we approach the bed? It may well be that all the care in relation to this lady has all been well-recorded in her file: the measurements, the results, everything related to the patient's safety ... But is a little more than this not possible? What went on inside her and who listened to her? The lady will never fill in the patient-satisfaction questionnaire. No-one will take any further interest in her. Yet I will recount her story and continue to recount it.

Disobedience as counterforce

Caregivers such as this nurse have been touched. Their indignation and disappointment betray that they have not only been intellectually touched, but that it goes much deeper. Initially there was frustration, but a specific situation has touched them even more deeply. They are sometimes literally physically sick from such situations: their stomach is churning ... They can no longer remain indifferent to what they see. They have been so greatly affected by what they

have seen – the other's personal distress as a result of the care system – that it moves them to action. In and through the experience of being moved and upset, they become aware that they must do something. If they then just keep to the rules or continue being obedient to the policy, they are simply fooling themselves. They then put themselves on the wrong track, one that turns them into the sort of people they do not want to (and cannot) be. The professional disobedience is to be found in precisely this sort of "motivation experience": they cannot do anything other than disobey the rules.

This is the second important characteristic of professional disobedience: that through being (passively) touched, strength is created to actually and actively bring about change. Anger releases a sort of counterforce, namely the strength to combat the de-personalised power of the system. The well-oiled functioning of the system threatens to become a goal in itself and people become its victim, both caregivers and care-receivers, the most vulnerable first. So this must change and be improved, otherwise the most vulnerable will again be left in the lurch. And that is unacceptable. Or, as disobedient caregivers put it: "I won't be a part of it".

The nurse who was touched by the lonely death of a vulnerable, elderly woman writes in her anger an open letter to the hospital's policymakers. She distributes her letter among her friends. A number of colleagues let her know that they also feel something is fundamentally wrong with the care in the hospital. One evening after work, an informal discussion takes place, attended by more than twenty colleagues. As a result, the decision is taken to go as a delegation to the management to discuss the matter.

Disobedience as a structural counterforce

Professional disobedience is not only a matter of not following the rules. Considered more broadly, it is a form of protest against an accepted policy and against the principles or methods on which the policy is based. It is often not the fight of one individual alone, but of a wider group of caregivers. They make up an interdisciplinary platform based on the experience: "together we are strong!".

This does not mean that professional disobedience cannot also be the disobedience of an individual caregiver. In such a case, the caregiver decides for him-/herself not to obey the rules in a specific situation, because these rules contradict his/her own conscience. We find an example of this in the story of a doctor in a hospital in Cologne (Germany) who opposed the prohibition on giving a woman who has been raped a morning-after pill. Looking more closely at this example, it is evident that there is a motivation for this disobedience. This disobedience relates to the concern as to whether the woman is prepared

to have a baby under these circumstances. Is it really disobedience if her rights and feelings are not considered at all?

As already mentioned, professional disobedience is often sparked by a very specific situation. The indignant caregivers see in that situation the manifestation of what is going structurally wrong in their organisation. It is questionable, for example, how ethical (in terms of care) it is to apply a general prohibition to the administration of the morning-after pill. The lonely death of an elderly patient is also a situation that is structurally incorrect. This is why professional disobedience, even if it is only the action of one individual, should preferably not remain hidden, but be given a public character. Otherwise no counterforce will be developed that is strong enough to correct what is going structurally wrong.

Ultimately, this is the purpose of professional disobedience. Huber makes it clear, for instance, that disobedience is necessary in order to ensure that ethical action is no longer disobedient. This is why it is important that the doctor in the hospital in Cologne, by analogy with civil disobedience, disregards the prohibition publically and by way of a statement. The risk of a sanction is high, but it is precisely by exposing him/herself to this risk that the doctor receives the ultimate opportunity to challenge the system publically.

The third characteristic of professional disobedience arises from this: it aims at correcting the structures and transforming the care organisation. The counterforce that develops is not rebellion for the sake of rebellion or protest for the sake of protest. Otherwise the direct result would be an ethical fanaticism that does wrong in the name of what is good (see in this context also Chapter 3 on mediocrity). Its intention is, in fact, to change something in the organisation itself. This is why Huber also emphasises the importance of peer support: counterforce can only be developed by more than one individual. He also speaks of the term *peer review*, by which he indicates the importance of putting what one individual caregiver experiences into the context of what others in the same organisation experience. To put it bluntly: if a caregiver is (or has to be) disobedient often, and does not obey the rules because they conflict with a "sacred conviction", then there is either something wrong with the system or with the conviction of that one individual. It should not be the opinion of an individual who is always against everything and everyone. Peer review is necessary to reflect on the legitimacy of the disobedience. Peer support relates to the necessary support of colleagues in order to avoid future disobedience as much as possible.

In short, professional disobedience is a question of ethics. In Chapter 7 we return to this comment. It is a rebellion for a better and more just care. It is therefore not (only) a question of introducing better working conditions or

exacting better working arrangements or pay conditions. It is essentially a question of activity that is directly focused on the care organisation, making allowances for vulnerable care-receivers and therefore for the benefit of good care. Professional disobedience distinguishes itself in this respect from the so-called 'White Anger' ('White Anger' is the translation of *Witte Woede*, a Belgian trade union for the health care sector). This anger also has better care as its aim, although in a more indirect way. The indignation in particular or whatever has caused the indignation and what has directly aroused it are different: professional disobedience is related to an indignation of the other, for the other. What has given rise to it is the specific other. The intended result of this disobedience is not only for that particular other – for whom the action sometimes comes too late – but for the third parties, for example the future others who will likewise become the victim of the system if it is not adjusted now.

Disobedience also brings about an ethical way of looking and thinking. It is for example the caregiver who, on the request of the family, refuses to force-feed an older person with dementia, who activates the discussion on feeding within the care institution. It is this disobedience that can lead to the vocalising of the demand for good care and which draws attention to the dignity of the person who is no longer able to defend his or her own dignity.

The desire for the best possible care organisation does of course always involve the risk – as in any battle resulting from moral indignation – of developing into a kind of holy war or ethical terror. The indignation is then so great that it cannot be reasoned with. The risk is that the indignation will turn into in a sort of challenge to be proven right, in which no change in the organisation is sufficient or enough, and that it is impossible to organise perfect care. Whoever fervently strives for the ideal of good care, whatever it costs, in deadly earnest and without taking reality into account, becomes tyrannical. For this reason, we argue for the pursuit of good-enough care. There is a place for disobedience in this pursuit, although it is a disobedience that is not devoid of a certain sense of reality. Neither is it devoid of humour.

Disobedience as speaking frankly

This brings us back to Marieke's mischievousness. She can hardly be accused of too much earnestness. Whether her unconventional behaviour is a form of disobedience remains questionable. We know too little of her motives for resewing her uniform, as she put it. Maybe she is just a little recalcitrant or a little naughty, but is she disobedient?

Much has already been said about disobedience. Disobedience arises in healthcare, and especially with caregivers who are strongly ethically concerned. Professional disobedience can, moreover, make the organisation more ethical.

In such a context, disobedience is a very important 'virtuous vice'. In what follows, we look more closely at this conviction. This should help us to discern when disobedience is permissible – or, in fact, when disobedience is necessary for the sake of better care. Even if "having to be disobedient" appears to be an enormous paradox. In terms of the disobedience under discussion, it is not a question of subjective capriciousness or desire or the expression of a contrary character. Neither is it a question of something that is externally imposed as some sort of 'law'. It is much more a sort of duty that is sensed from within and which makes one speak out from a sense of having to speak out, *having* a strong urge to no longer keep silent.

Speaking frankly is not just saying whatever you want to say

Disobedience has much to do with an imperative. By definition, disobedience means: not doing something that is imposed. In terms of professional disobedience, it is a question of caregivers not behaving as required, or at least calling the required behaviour into question because it is in contention with an imperative sensed from within. "I cannot and will no longer be silent", the nurse writes in her open letter. The system clashes on a basic level with what she considers to be good-enough care.

On the basis of texts from ancient Greece, the French philosopher Michel Foucault developed the idea of speaking frankly (parrhesia) as an important instrument on behalf of democracy and a free and responsible society (Foucault 2009). Speaking frankly is not the same as saying whatever comes to mind (whatever you think, whatever is in your heart). Neither is it the expression of subjective caprice or a bad character or rudeness. It means speaking the truth without pretence, without conditions, without hollow words and without great rhetorical embellishment which may disguise or mask the truth. In this sense, the parrhesia opposes the narrow hypocrisy as discussed in the fourth chapter. Whoever speaks frankly, does not only express his/her own opinion, but is him-/herself completely tied to the truth; it is not only a question of pleasing words, but it is speaking from what is within. As the nurse puts it, you cannot do otherwise than speak: it is a duty calling from within. This is not imposed from outside, but an internal must, a sense of duty that is at the same time characterised by longing and urgency. To qualify as frank speech as understood by Foucault, it should be a question of making an opinion publically known, involving taking the risk that it may not be accepted. Speaking the truth means that the person who speaks can hurt, anger, irritate the other and even evoke a reaction from the other that is intended to silence the speaker. Speaking the truth therefore demands courage. This is certainly true in the context of power, where the person who speaks frankly is not actually given the room to speak so freely (Devos 2013; Papadimos & Murray 2008).

The concept of speaking frankly also continues to have an influence in healthcare as a metaphor for the disobedience of caregivers who draw attention to more just care structures and to vulnerable care-receivers who are unable to defend themselves. Just as speaking frankly has an important role in democracy, it also plays a significant role in care organisations. As with every system, the pursuing of efficiency in a care organisation threatens to become a goal in itself and thus to result in a coercive system. In order to avoid this, the system itself will benefit from a culture of frankness, a culture in which caregivers from time to time speak their mind and speak in the name of those who are likely to become the victim of the system. This concerns troublemakers who are critical and who ask awkward questions, precisely because they are not the system, although they are very much part of it. The parrhesiastes uses the complex freedom of "disengagement in the engagement", that is, maintaining sufficient distance while participating in the system. To a certain extent, we go here beyond Foucault, who puts speaking frankly strongly - although not exclusively – in the context of the care for oneself. In that context, it can however also help healthcare workers not to remain burdened with indignation, frustration and dissatisfaction. Whoever trains him- or herself to speak frankly - "I am angry because ...", "I feel like this because ..." - learns to give expression in an acceptable way to those things that otherwise lead to a burn-out, to indifference, to detached care, or to disproportional outbursts of displeasure.

Speaking frankly with the aim of a more just care organisation

An organisation with a culture of frankness satisfies two conditions. The first condition is that there are people who are sufficiently professionally disobedient. This is to say: people who are sufficiently vulnerable to allow themselves to be touched by what goes wrong and who above all have the courage to speak frankly. Care organisations themselves play a role in this. Parrhesia is then perhaps not a skill, but an attitude, and according to Foucault, a way of being that is related to the virtue. It is an attitude that can be cultivated, exercised and trained. When doctors have had mentors during their training who have attached importance to frankness, they themselves are then aware of the ethical power of speaking frankly in their team. Whenever nurses learn, through their superiors and mentors, to articulate that they are indignant and why this is the case, then they find even more strength and the necessary selfconfidence to speak frankly. In this way, they avoid entering into a pernicious form of hypocrisy or of putting destructive energy into sneaky and malicious underhandedness that is difficult to verify but which does ruin the atmosphere. The culture within the organisation must of course also be of such a nature that it grants sufficient room for speaking frankly. When this is punished, however, no one will continue to dare to be courageous enough to take the risks involved in speaking frankly. Foucault is convinced that a culture of speaking frankly can only become organised, develop and stabilise in what he calls the *parrhesiastic* game. A game is always played with two parties. The *parrhesiastic* game is a question of someone who speaks the truth and the other who accepts this truth, acknowledges it or is at the least willing to consider it, however difficult and troublesome that is. This explains the second condition which needs to be met by a culture of frankness: the organisation must be a receptive receiver. The management must be open to criticism and must recognise that people who speak frankly are essential to keep their organisation focused on good care for vulnerable people. The pact between the person who risks speaking the truth and the person who is prepared to listen to it forms the heart of what Foucault calls the *parrhesiastic* game. He writes:

It is not the argumentation, the monologue, but the dialogue with questions and answers that is characteristic for the parrhesia. Dialogue is then an important technique for playing the parrhesiastic game. Personal discussions offer the best opportunities to speak frankly and truthfully, precisely because it is possible to have such discussions without rhetorical manoeuvres and embellishment.

- Foucault 2009:17 (authors' translation)

On the basis of the nurse's open letter and the movement that grew from the grass roots, a consultation was organised. The sort of consultation body was created that plays an important role in Foucault's *parrhesiastic* game. It is becoming in particular the place where hospital managers more frequently seek feedback on policy and open it up to questions and where the people who carry it out can make an effective contribution to a more just and more caring hospital through their frank speaking. And this in dialogue with a hospital management that does not have the opportunity to hear the voice of the patient in any other way than by way of letters of complaint and who are faced with the immense challenge of leading the hospital through an economical-financial and legal jungle.

Speaking frankly is speaking in the name of the most vulnerable

By now it has become clear that disobedience is related to the goal and the quality of the care organisation itself. It demands courage and peer support. It presupposes an organisation that is a receptive receiver and open to criticism. Open dialogue means progression. Not only the interest of the professional and financial organisation is important, the vulnerable individual is the prime focus. Disobedience that aims at destroying the system is difficult to accept, unless it is evident that so much is going wrong in and within the care organisation that it needs to be called into question in its entirety. Sometimes a complete revamp is needed, demanding a total and radical approach; this is exceptional,

however. In general, it is a question of an adequately qualitative organisation, which has need of a corrective leverage in its midst. It is not possible to offer carefulness independent of or outside the system. The care organisation is in itself a sort of ethical correction in healthcare. It is not only a question of this one care-receiver who requires care: there is another one, and yet another one, and so on. There are care seekers who need "similar" care and for them it is precisely organisation, structure and the system that are needed. Without management in healthcare, which manages and distributes among other things such a scarce matter as time, there is a great risk of arbitrariness where much time goes to the one care-receiver at the cost of the (many) others who are just as in need of time. Those many others suffer if care restricts itself to goodness in only that one care relationship. The organisation itself, the management, and by extension the healthcare policy on the level of society as a whole, brings about a just distribution of means, an as accurate as possible estimation of the care needs, and seeks to accomplish this as efficiently possible. There would be no question of fairness without organisation. Then there is only the individual goodness that is absolutely not just, and without justice there is insufficient caring for all and thus inadequate good care. In this sense, organisation and management are important ethical means in as far as they lead to care for many being taken to heart as much as possible. The care organisation itself ensures that goodness is also just, and that good care is not only for the person who shouts the loudest or pays the most.

A problem is created of course if the system has a definitive regime or becomes a goal in itself. This is the reverse side of organisation and management: the innovation of the system for the sake of innovation itself or pursuing efficiency for the sake of efficiency as the greatest good. This is the risk to which every care organisation is exposed: that it is no longer focused on the vulnerable individual, but only on the organisation itself as a successful professional and financial whole. Where all attention is focused on the organisation, there is a danger that the tears of the unique other will no longer be noticed, says Levinas. He continues:

In order for matters to proceed in a dignified way, it is absolutely essential to emphasise the responsibility of all, for all, in relation to all. In social systems and organisations, individual consciences are needed, for only they are able to see the violence that is created by the good operation of the organisation itself. Only the responsible I is in a position to see the secret tears of the other, which are produced by the good operation of the organisation. The unicity of the responsible I is consequently indispensable for guaranteeing the justice that the organisation seeks after, but which, on the basis of the operation of the system itself, overlooks the vulnerable other.

- Levinas 1994:80-81 (authors' translation)

Disobedience must lead to a correction of the system in as much as it allows the voices of a vulnerable care-receiver and caregiver, who are in danger of becoming the victims of the system, to speak. This is precisely what the nurse, who tells the story of the lady who died alone, has done. By recounting this story, the nurse brings in the rights of the unique other and none other than the rights of the patient who can no longer defend her rights herself. To put it in an even broader perspective: disobedience serves to bring in the story of human rights, to be understood as the rights of the unique, vulnerable other. Those rights remain the permanent point of reference for the care organisation.

Disobedience that creates room for the "small goodness"

Disobedience not only plays a role in a culture of frankness and in the adjustment of the organisation toward more justice, it also plays an immense role in the cultivation of ordinary, day-to-day caring. Marieke, the trainee nurse in the novel *There Used to Be a Future (Vroeger was er later)* by Marynissen (2012), comes once again into the picture in this context. The disobedience of the trainee nurse probably fits into more or less everything that has been said up to now about disobedience. And yet she makes something happen: the "small goodness" as described in Chapter 3, and also elaborated upon in Chapter 7.

Levinas takes this idea of "small goodness" from the novel *Life and Fate* by the Russian author, Vasily Grossman, who writes:

In addition to the good that is great, there is also an everyday human goodness. This personal goodness of the one person toward the other is a goodness without witnesses, unremarkable and unreasoning. We could call it an insignificant goodness. However, on closer inspection, this insignificant, personal, co-incidental goodness is eternal. Even in atrocious times [...] this paltry goodness still exists scattered over life in tiny particles. This foolish goodness is what is human in humanity, what distinguishes humanity, what is the highest that the human spirit can achieve. This simple goodness is indeed powerless, but as beautiful and as powerless as the morning dew. Goodness is powerful as long as it is powerless! As soon as humans attempt to draw power or a universal idea from it, then they are lost; then it turns pale, fades away and disappears. The impotence of the unsightly, helpless goodness is the secret of her immortality. She is invincible, great in her simplicity: the spark and the meaning of our humanity!

- Grossman 2012:411-414 (authors' excerpt and translation)

Levinas emphasises that this small goodness specified by Vasily Grossman forms an important and indispensable counterweight to the depersonalisation of every social, economic, financial, legal and political organisation, and

therefore – from the perspective of this book – of every care organisation. It is namely in and through the small goodness of the individual caregiver that the tears of the vulnerable care-receiver are perceived. This small goodness allows justice to be done to each individual person. Levinas calls this the "noble casuistry": only through this small goodness do caregivers allow their judgement to be based on the individual person whom they have before them and take the specific situation of every 'case' into consideration. In brief, only in and through this small goodness are people (and their situations) approached not from the point of view of the care organisation, but precisely from their irreducible unicity.

Characteristic of this small goodness is that it never allows itself to be completely organised or managed, let alone cast into protocols and procedures. This small goodness has in fact even a hint of a tiny bit of disobedience. It is then a question of a disobedience that knows how to respond in a flexible and creative way to protocols and procedures, to policy and other sorts of norms that stipulate and lay down what good care is. These naturally always have shortcomings. It is precisely in Marieke's small, mischievous disobedience toward the norms and regulations of the residential home on how a caregiver must enter a resident's room to wash him, that Paul experiences small goodness.

In a work with the title Silent Values (Stille waarden), Bart Brandsma (2010) of the organisation Curamus writes about the importance of silent (but intrinsic) values in healthcare. He means more or less what Levinas calls "small goodness" (Levinas 1995:199). It is about the secret of healthcare. It is about what caregivers just do, about which they cannot speak or even reflect on. It is however precisely with these silent values, which make the difference in healthcare, that he is concerned. Brandsma points out the danger that lurks in every care organisation, namely the danger that the silent values will be drowned out by vociferous norms. These norms are loud because they are of central importance in a care organisation: the management and the work floor are dominated by the thinking in terms of systems, goals and efficiency. That thinking, Brandsma confirms, also has an unmissable good side to it. However, good care will cease to exist if the silent values become completely choked by the vociferous norms. An equilibrium needs to be found between the world of systems and the living environment, between a well-oiled care organisation and small goodness as an audacious form of small disobedience.

Every so often, this equilibrium can only be found by a caregiver who disregards the blaring/outspoken norms in order to be true to the care-receiver and to not leave this person in the lurch – thanks to the small goodness and the noble casuistry that incite the small disobedience. In this the small goodness makes it imperative to disobey, but then in a gentle, unpretentious, modest way. By being disobedient to the blaring/outspoken norms at certain moments, the caregivers

create the space where the silent values can flourish. It is a disobedience that creates the space for the "small goodness". We therefore call it small disobedience. And we do so to distinguish it from the great disobedience of speaking frankly, loudly and publically. Analogous to the small goodness, the small disobedience is gentle, silent, unpretentious, modest and without triumph. It takes place unwitnessed. It does not scream blue murder, and it certainly does not establish what may be called great justice. It is seemingly naive, since the simple souls who practice this small goodness seek to put out the fire of wrong with a syringe, as Grossman puts it or, according to Levinas, with a water pistol. But seeking to extinguish is seeking to extinguish. And it is the smouldering fire under the ashes, the spark of the human in humankind: the infinite in the finite!

Care incentives

The following questions and activities can guide the caregiver in dealing with disobedience:

- 1. In what sort of situations do you catch yourself being non-cooperative and disobedient?
- 2. Is this something you do: saying "I am very sorry, but I am not going to do this anymore"? If you say this calmly, what reactions do you get? If you say it with irritation or heatedly, how do others react?
- 3. Disobedience begins by becoming aware of your own feelings. When is it for you a question of overstepping a boundary? Under what circumstances do you say to yourself: "Not with me!"?
- 4. In relation to which rules would you like to be disobedient? Do you do this openly and/or do you discuss it with other colleagues?
- 5. To whom do you speak frankly and openly? To whom do you not voice your opinion? What makes the difference?
- 6. Among nurses, a mutual social pressure is sometimes present: you may not do more than another, because then the same care is expected of that person. To what extent do you obey the informal group norms? Do you remain frank in this context or does this restrict your spontaneity in giving care?

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CHAPTER 7 CARE ETHICS IN THE WAKE OF EMMANUEL LEVINAS

A PHILOSOPHICAL POSTSCRIPT

In his novel *The Children Act*, Ian McEwan (2014) describes to great effect a case in which the sexagenarian London judge, Fiona Maye, is called upon urgently to pronounce judgement. The case involves the seventeen-year-old Adam who has leukaemia, and who refuses a vital blood transfusion on grounds of his faith conviction and that of his parents. The boy and his parents are Jehovah's Witnesses. The hospital urges the judge to overrule the decision of this (still) underage boy in order to save his life. His parents request that his refusal and the reasons therefor be respected. They point out that he is almost of legal age and is, moreover, exceptionally well-advised, convinced and intelligent.

Going against customary practice where a social assistant interprets the perspective of the underage person, Judge Maye visits the boy in the hospital and begins a conversation with him in order to determine what is at stake for him. She listens to Adam and is touched by his story and his personality. Adam writes poems, of which she reads a few. He also likes music and sings an old Irish ballad that has a familiar melody, to which she sings along. After their conversation, Judge Maye finally arrives at the decision to have him receive transfusion. After the case is closed – and indeed as a consequence thereof – Adam distances himself from his parents and their faith. Adam and Judge Maye begin exchanging letters – another action contrary to custom. Adam will not let go of Fiona Maye, and neither she of him. When, at a given time, he secretly follows her to Newcastle and seeks her support, she kisses him and sends him away with the firm reprimand not to contact her ever again. The novel ends in tragedy, leading Judge Maye to make the following reflection, reminiscing on their encounter in Newcastle:

She should have been flattered. And ready. Instead, on a powerful and unforgivable impulse, she kissed him, then sent him away. Then ran away herself. Failed to answer his letters. Failed to decipher the warning in his poem. How ashamed she was now of her petty fears for her reputation. Her transgression lay beyond the reach of any disciplinary panel. Adam came looking for her and she offered nothing in religion's place, no protection, even though the Act was clear, her paramount consideration was his welfare. How many pages in how many judgments had she devoted to that term? Welfare, well-being, was social. No child is an island. She thought her responsibilities ended at the courtroom walls. But how could they? He came to find her, wanting what everyone wanted, and what only free-thinking people, not the supernatural, could give. Meaning.

- McEwan 2014:12

Note: Roger Burggraeve took the lead in this chapter based on his in-depth knowledge on Levinas. Additional comments were made by the co-authors of this book. See Burggraeve's writings, among others: *The wisdom of love in the service of love. Emmanuel Levinas on Justice, Peace, and Human Rights,* Milwaukee: Marquette University, 2002, 2003 (2nd ed.), 2007 (3d ed., with one correction and new cover), 213 pp.; *Proximity with the Other. A Multidimensional Ethic of Responsibility in Levinas*, Bangalore (India): Dharmaram Publications, 2009, 152 p. For an extensive Bibliography of Burggraeve: J. De Tavernier, J. Selling, J. Verstraeten, P. Schotsmans (eds.), *Responsibility, God and Society. Theological Ethics in Dialogue (Festschrift Roger Burggraeve)*, Leuven-Paris-Dudley, MA, Peeters, 2008. See also the Literature at the end of this chapter.

Care relationships require responsibility. This is the adage of care ethics. Stephanie Collins likewise summarises care ethics in a one-liner: "Care dependency generates responsibility" (Collins 2015). Adam's care dependency made Judge Maye responsible. Her attempt to define the concept 'well-being' in a distant and abstract, almost principled, manner collided with the concrete, direct way in which the well-being of Adam took shape in the care relationship that arose between her and him. She now discovers that she was of significance to him. Not through her superb administration of justice, couched in grand values and principles, but rather through what she meant to him.

Responsibility for the other does not reveal itself as a spontaneous élan but as a form of unease, as we have already made clear in the first chapter on the small vice 'Antipathy'. With reference to the philosophical ideas of Emmanuel Levinas (1905-1995), we also discover how we are responsible for the other even before we are able to make the choice to take up responsibility for the other. The unease that this can usher in is perhaps indeed that which we can call ethics.

In this philosophical postscript, we enter in more depth into this view on (care) ethics. We would like to clarify, along with Levinas, that the ethics of the small vices concerns precisely how to deal with the inescapable tension that arises between different forms of responsibility. Anger, as situated in Chapter 5, can thus be seen as an attempt at dealing with the tension between the ethical responsibility for oneself, for one's own attempt-at-being, and the responsibility for the other. The small vice of disobedience, as presented in Chapter 6, is then mainly an attempt at dealing with the collision between the responsibility for this one other, and the responsibility for the many others and therefore with the organisations of care. In short, the ethics of the small vices teeters on the edge: not taking the edge out of the ethical tension whereby ethics disappears from care, but keeping the ethical tension indeed liveable and endurable by means of giving it a place in daily care.

The ethics of the small vices finds its roots in the philosophy of Levinas. In this postscript we now expose these roots and we clarify philosophically how we see the care ethics of the small vices as an ethics of responsibility. The language and tone of this postscript deviates from the chapters in this book because it is philosophical and foundational, reflecting on the anthropological and ethical basis of the actual care practice. Its focus is thus not on the elaboration of an ethical practice of care but on its philosophical underpinnings. We start this postscript with Levinas' description of 'my' relationship to the 'other', in terms of which the aspect of involvement with oneself as well as with the other will be investigated. In this first part, we will discuss the "responsibility in the first person". Afterwards, in the second part, we will make clear how the relationship to the care recipient displays a radical ethical character. We will speak of the

"responsibility in the second person". In the third part, we will make explicit the social dimension of this responsibility, whereby the organisation of care is also deepened ethically. In the fourth part we will consider what this means for the definition of the caregiver as person, leading us to a reassessment of our image of being human and of responsibility as 'condition humaine'.

Caring for myself ("responsibility in the first person")

Levinas' very unique approach to responsibility can only be fully understood when we situate it against the background of his view on responsibility in the first person. According to Levinas this responsibility must be taken very seriously precisely because it is the foundation and dynamism of who we are, literally "to be" and "have to be". Moreover, it plays an important role in all caregiving since the caregiver is not the only 'I' that is concerned with him/herself, but the client, or the other, is also concerned with him/herself. What the dimension of 'I-involvement' means for caregiving will become clear especially in the second part of this chapter.

When we sum up the feelings, thoughts and images that we associate spontaneously with responsibility, then it is always about forms of involvement with oneself. We perceive that our existence is a responsible existence, in the sense that we 'have to be', that we discern that our existence is no mere fact but is likewise a task or mission wherein a certain exigency is involved. Here 'I-myself' am both the starting point and the 'subject' rather than the 'object' or the goal of responsibility. From within myself, within the dynamism of my existence itself, I feel driven to take up the care for myself and vouch for a personally meaningful existence. I am therefore responsible for that, as they say, in the sense that I am also answerable for it.

Using a term of Spinoza we can characterise this responsibility in the first person as "conatus essendi" or "attempt at being", i.e. literally the attempt to be (Levinas 1981:4-5). The human person becomes an 'I' because one does not simply exist trouble-free but does so in a struggle in order to be – one is entangled within a "struggle for life". I am concerned about my being and try stubbornly to maintain, defend and develop it. As a first person that proclaims oneself as 'I', I manifest myself as an exceptionality that takes pleasure in my own exception, in other words, concerned with my own happiness or wholeness. In that sense, my personal existence is simply characterised by self-interest. This self-interest, however, should not be conceived of as an ignoble and contemptible perversion of immoral egotism, but rather as a 'natural' and positive egocentrism, as a healthy self-love. As a finite and needy being, i.e. as a creature of 'deficit', limitation and all sorts of lack and negativity, a healthy

'I' cannot but be concerned with oneself and one's being and try to counter and abolish – literally to 'full-fill' – the emptiness. By means of my finitude and neediness I am what I am and at the same time not what I am. I posit myself as being in being, but do not yet possess my being. I am myself by not coinciding with myself, whereby out of my own essence I am 'driven' to surpass myself as deficit and out of this subjective, singular interest in existence I strive to maintain and develop myself, meaning to say to succeed in life and to achieve a certain perfection, in other words to become happy. The 'I' is literally a 'being-foroneself': it lives out of and for oneself in an assiduous activity to become even more and even better 'one-self'. This attempt-at-being, moreover, points not only to 'incompleteness' but also to 'alienation'. In various respects the human person is robbed of one's being. I posit myself but it happens in my absence. I confirm myself but at the same time I lose myself. I lose myself amidst the objects; I become separated from the centre of my existence because of time, space, all sorts of distractedness, fragmentation and forgetfulness. Hence, according to Ricoeur (1992:1-25), the 'I' takes place as an aspiration, a striving, a desire or 'longing-to-be' (désir d'être) and 'endeavour-to-be' (effort d'exister) to which freedom is also immediately linked, not as a static givenness but as a goal to be conquered, a dynamism whereby the subject constitutes itself. We are not free, we still must become free. In this regard, freedom is thus only possible as longing and as 'prise de possession', as 'work', as conquering and appropriation, or as re-conquering and re-appropriation of an incomplete and alienated existence. From the start or the introduction of our book, we called this the non-heroic fragility of the caregiver, as further elaborated through the chapters on laziness (Chapter 2) and on mediocrity (Chapter 3).

Now Levinas (1981:15-16) does not ascribe an ethical significance directly to that since for him the attempt-at-being is still an expression of the 'natural' dynamism of existence, insofar as a 'not being able to do otherwise' remains lurking therein. For him, ethics in the strict sense then begins only in the appearance of the other. Ricoeur (1992:21-22) takes on a different standpoint and ascribes unambiguously an ethical significance to the longing-for-being. We rather follow Ricoeur here because the longing-for-being in its own dynamism creates space for and even requires the commitment of freedom. In subjectivity there is more at hand than simply a 'natural' process of existence. It also concerns an active performance of the human person, who must make considered decisions and choices in order to give direction to one's longingfor-being and extend it into a real dynamism of freedom. The concept of responsibility that is linked here is then something that is not added onto freedom from without, but something that qualifies the dynamism of freedom as project from within. This dynamism manifests itself as a demand or a duty towards self-realisation, and thus also to 'self-care', that not only preventively avoids harming one's own life, health and psycho-social development but also endeavours positively to develop them and give them meaning, without lapsing into the extreme of an obsessive preoccupation with body and health. This duty towards a balanced self-care, however, does not come from without but is, on the contrary, intrinsic to the dynamism of striving for the subject itself. The 'duty' to become and to develop oneself is the longing-for-being itself, or rather 'duty' is its ethical expression. In this regard, the deepening of the longing-for-being coincides with ethics. We can certainly speak here of a must, but this is only true on condition that we do not confuse this 'must' with a 'law' that comes from elsewhere. It is made apparent here how the 'law', understood precisely as an external, objective demand, is not the first moment in ethics. Thanks to the longing-for-being we discover a 'more primitive' and 'more original' moment, one that Ricoeur also labels as ethically fait primitif or l'originaire éthique (Ricoeur 1992:171-180) namely precisely the intrinsic demand or rather the urge that reveals itself as the task and the will to substantiate oneself. This means that freedom is given as a task, and is thus anything but a non-committal or at most tragic 'accident': it must become itself. This means that freedom feels responsible for itself, while paradoxically it is at the same time the ground for this responsibility: it is simultaneously both its condition and its goal. Here, freedom and responsibility are taken as synonyms and they refer mutually to each other. There is no responsibility without freedom, and vice versa.

Here, however, we must guard against a misunderstanding. There is an essential aspect still lacking in the sketch on self-realisation above: selfbecoming can never imply an immediate identification with oneself. There is no direct appropriation of existence possible that has a short route, i.e. there is no way to have immediate self-awareness. I cannot maintain myself as a free and self-responsible longing-for-being by means of coinciding with myself immediately, time and time again, thanks to an internal act. In such case I remain stuck in the empty immanent tautological circle of "I am I" ("A is A"). On the contrary, I must let go of myself in order to find myself. I must exteriorise myself in order to give real meaning and content to my interiority. Freedom can only realise itself in and through the works wherein it objectifies itself. As such my freedom is an unknown 'X': I cannot see 'it', I cannot even prove that I am free. I can only 'believe' that I am free, I can only posit myself as freedom. It is precisely this absence of a 'seeing one's own freedom' that would offer me the certainty of a fact, that explains why freedom can give testimony about itself in and through its 'works' (actions and objective expressions). I can thus only start from the belief and the conviction that 'I can', that I am what I can, that I can what I am. There is talk precisely of responsibility, and thus of ethics, because 'belief' – even though it is called a light – is a blind light where productivity must prove and conquer itself in and through a whole activity, an entire life. Freedom as the original confirmation of existence thanks to the

longing-for-being, is not enclosed in any single, separate act, and no single deed or work exhausts it. The intimate testimony of the 'I can' thus requires a course, a duration that still must come. The ethical life that goes hand in hand with freedom as longing consists in 'making oneself give' and not in 'seeing oneself give'. Only in and through the 'realisation' (*Verwirklichung – Hegel*) in activities and all sorts of objective forms can freedom, which does not possess itself but is only given to itself as longing, realise itself.

With this task towards responsibility, which is interwoven with freedom itself as longing and mediation, comes a unique form of error and guilt as well. This ethical negativity already comes up quite early, not as a transgression of an extrinsic commandment or prohibition, but rather as a consequence of the inadequacy that is experienced between the longing-for-being and every 'work' or objective form of freedom as longing. The negative here does not arrive from without but from within: the negative is negative towards the longingfor-being and thus comprises the dynamism of the longing-for-being itself. It concerns that which is negative in the 'deficit', now not as an original given but as a 'failure' (échec). This notion indicates the distance between the longingfor-being and every realisation, precisely insofar as the human person does not succeed in one's active exercise of freedom to bridge this distance according to one's wishes. I remain below par on my own freedom as ideal and project. This is no coincidental distance, but a 'being-out-of-step' that is constitutively bound with the being of the concrete subject itself, that only possesses its freedom as longing and mediation. This gap of failure is not only experienced in active existence as a tragic and unfortunate contingency, or as 'fate', but also as 'failing' and 'error'. I fall short with regard to my own freedom that only falls upon me if I vouch for it. The awareness of guilt thus still comes up even before there is any mention of the external, objective laws and prescriptions, against which one sins by means of transgression. It is an awareness of error that occurs on the level of the dynamism-of-being, precisely when the human person appropriates this dynamism-of-being and tries to substantiate it as a project. The awareness of error and guilt that lies interwoven here is thus equally primary and original as the ethical fait primitif of the longing-for-being itself precisely insofar as shortcoming is inherent to the acting and 'working' subject in its sense of 'inequality' and 'inadequacy' towards its own affirmation of freedom as self-confirmation.

Caring for the unique other ("responsibility towards the second person")

After having reflected on what at first sight is most near and recognisable, namely the care for oneself, or the 'I that is concerned about itself', we now would like

to enter into the encounter of this 'I' with the 'other'. What is central there, says Levinas, is the way in which the other appears to me, namely as a face, and likewise the way in which this 'manifestation' displays an ethical character in the sense that the face of the other arouses the 'I' towards responsibility. It will become clear along the way how this 'heteronomous responsibility' displays different aspects, with all sorts of implications for caregiving (Levinas 1979:66).

From countenance to the face of the other in need of care

With Levinas we begin with the fact that the other appears to us "from elsewhere" – from without – and thus enters into our existence unasked. To indicate this fact, in his first major work *Totality and Infinity* (1979), Levinas uses the expression "the epiphany of the face". The other appears, and this according to a double heteronomy. Its 'appearance' escapes both the initiative of the other and my initiative. I am confronted without prior notice with the other, without it being in the intention of the other to take on this confrontation with me. One can thus speak of a double "in spite of", namely "in spite of myself" and "despite the other".

The question now is, what is precisely meant by this appearance of the other or epiphany of the face. At first sight, it seems simple; a face is indeed a face, but upon closer inspection we are confronted immediately with a rather obvious misunderstanding. When we hear the word 'face', we spontaneously associate this with the physiognomy, the facial expression, and in extension the character, the social status and economic situation, the cultural background, the past and the 'context' out of which the other becomes visible and describable to us. The face simply seems to coincide with what the other allows 'to be seen' and 'to be presented' by means of its appearance. By this literal 'option' for the other we believe we are able to 'determine' the other, whereupon we tune in our reactions and practices. Even in various forms of caregiving we start with a 'diagnosis', literally a methodical and technical professionalised 'observation', whereby on the basis of our foreknowledge of 'problem-images' or 'symptomatologies' we are able to state a diagnosis with an eye to a prognosis and treatment or solution to be applied.

What Levinas means by the face of the other, however, is not one's physiognomy or one's appearance but precisely the remarkable given that the other – not only factually but also and especially in principle – does not coincide with one's appearance, image, photograph, presentation or evocation. "The other is invisible" (Levinas 1979:34). Hence according to Levinas we actually cannot speak of a 'phenomenology' of the face since phenomenology describes that which appears. The face, however, is that which eludes our gaze in the

physiognomy of the other that is turned towards us. The other is 'different', irreducible to one's appearance, and therein the other reveals itself precisely as a face. Naturally, the other is visible; naturally it appears and it evokes all sorts of impressions, images and presentations whereby the other is describable. Naturally, we can come to know quite a lot about the other on the basis of what the other allows 'to be seen': its psychology and sociology, its familial, social, ethnic, cultural and ideological background. The other, however, is much more than its photograph, or rather it is not only in fact more – in the sense that I am able to discover even more about the other – but it can never be adequately represented and encapsulated in one or the other image. It is essentially, and not only factually or temporarily, a 'receding' and 'surpassing' movement. I can never pin down the other or equate it with its figurative form and various characteristics (Levinas 1985:85-86). Its appearance takes place paradoxically as a withdrawal, literally as a 'retreat' or anachorese. The face imposes itself as the explosion of its own image; it deconstructs its appearance by receding from this appearance. The face continually disproves its own face: it is its very own iconoclasm. Its epiphany is always a breaking through and disconcertment of this epiphany, whereby the other always remains enigmatic, and precisely through that it imposes itself as the irreducible, separate and different, foreign, in short as the other par excellence (Levinas 1979:78). The other is unconquerably 'other' because it escapes permanently every attempt at presentation and diagnosis. The epiphany of the face makes all curiosity ridiculous (Levinas 1979:46). This is what Levinas means by the "irreducible alterity" of the other.

It will become clear below how this radical, heteronomous alterity "coming from elsewhere" implies a very specific form of responsibility, namely a responsibility that is essentially marked by heteronomy (Levinas 1987:58). It does not start from me towards the other, but from the other: it is "by the other" even before it is "for the other". It finds its origins not in my initiative, but precedes my freedom. In my self-concern I collide inadvertently with the other. In spite of myself I am confronted with the other. Through the other, or rather through the epiphany of the other – precisely because the other does not make a decision about it – I am made responsible without being asked. In the second major work of Levinas, Otherwise than Being or Beyond Essence (1981), we then read the following as an ever recurring refrain: "une responsabilité antérieure à la liberté" ("a responsibility prior to freedom") (Levinas 1981:123). That is why he also characterises it as *an-archic* and pre-original, in the sense that it does not begin in my freedom, which posits itself as archè or 'beginning' and origin of personal meaning (Levinas 1981:10). It takes place for me outside of my abilities and knowledge: no longer am I "the master and possessor of the world" (Descartes). For Western, especially modern and late-modern ears, that since the Enlightenment have been used to thinking of responsibility as

the extension and even synonym of autonomy and freedom, this may sound shocking. How can freedom be put out of the game in responsibility? Is a heteronomous responsibility not a *contradictio in terminis?*

It is through the fact that the other presents itself before me - a fact that utterly escapes all my capabilities – that I am held responsible, and this in the strictly passive sense of the word. I likewise take no initiative in making myself available or taking a passive stance, so that I can be held responsible. That still would be an active passivity. It is about a passivity that is more passive than all passivity, since I cannot foresee nor plan the entrance of the other into the circle of my subjective existence, nor can I open myself up to it beforehand in all willingness. It is thus not about a responsibility that rests on sympathy, willingness, generosity or "altruistic will" (Levinas 1981:111-112), but rather on a conscious turning towards the other that is based on myself - the self that is mine. It is a responsibility that takes place in spite of myself precisely because it breaks into my existence 'from elsewhere', utterly unforeseen and uncontrollable, and - against the entire meaning of my conscious and active creation of meaning and freedom – turns my existence upside down. The other presents itself as unpredictable and surprising, stronger still as a traumatising fact par excellence, in this regard the source of the purest empiricism or the strictest experience, a real event that falls upon me in the literal sense of the word. To summarise: the other displays the character of an 'extra-ordinary', literally 'e-norm-ous' exteriority, out of which a heteronomous responsibility ensues (Levinas 1979:294-297).

Ethical relationship of care begins as crisis

According to Levinas the vulnerability of the face lies at the same time in its radical, heteronomous alterity, with which its ethical significance is likewise clarified (Levinas 1981:291). As 'face' the other is vulnerable and can easily be reduced to one's appearance, social position, 'performance', health or medical profile, family, social or cultural-religious 'context'. As the 'in-visible', i.e. irreducible to one's phenomenality, the other appears by means of not appearing; in other words the other appears in a paradoxical manner as the homeless, the widow, the orphan, the foreigner, in short as the one who does not belong in my organised world - a world that I am precisely going to organise as 'my world' on the basis of my natural 'fear for myself' and 'selfinterest'. The other escapes not only my foresight, it also does not belong to its scope; the other literally falls out of the boat. The other is located literally in the 'extra-territoriality' and 'u-topia' or 'no-place'. It is precisely for that reason that the face is so vulnerable in its countenance. It is after all the appearance of the face as countenance that invites me as it were to reduce the other to its face, in other words into its medical and psycho-social diagnosis, problematic

or medical profile. This 'invitation to reduction' is dependent not only on the vulnerability of the face but also on the mode of being of the 'I', to whom the face appears. In the preceding section we described the dynamic self as a 'striving for being' wherein 'my own being' acts as origin and goal. This concern for the self leads to my approaching the other from an 'interested' position that tries to give to this other a place, function and meaning within its own project of existence (Levinas 1981:4-5).

This also applies to the way in which I approach the face of the other. On the basis of my spontaneous attempt-at-being I aim at affirming myself as 'freedom' and developing myself by means of drawing the other towards me and integrating the other as a 'function' or interesting possibility in my existence. Thanks to my spontaneous or thoroughly methodical observation – 'view', in the literal sense of the word – I strive to get and hold the other 'in view' or 'in my line of sight'. And this perception takes place not out of 'contemplative' considerations that intend to respectfully 'reflect' the other and 'let it be', but out of concerns for self-interest. If I succeed in discovering or 'unveiling' the other, I can also know how I can deal with the other and how I can integrate the other in one way or the other into the realisation of my autonomy and project of existence. That is why the face appears as weakness par excellence insofar as it can precisely be reduced – on the basis of its appearance and on the basis of my perception - to its countenance. In this regard Levinas states in a paradoxical manner that the other appears before me as the temptation to kill: "as if inviting to me to an act of violence" (Levinas 1985:86). Through its appearance the face exposes itself to me, it delivers itself as it were to me defenceless against my 'unashamed glances' that observe and explore. The nakedness of the face is an 'upsetting' nakedness that testifies to an essential poverty. The evidence for this is that the other tries to camouflage its destitution by hiding itself and erasing itself as much as possible or by giving itself an 'air' by means of posing, applying make-up or dressing up and looking good, in short by 'keeping up appearances'. This makes it clear that the other is aware of being exposed, and through its physical and psycho-social appearance invites as it were the unashamed 'observing' - literally 'voyeuristic' - 'I' to commit violence. By means of its 'countenance' and its multiform visibility the face challenges me as a self-interested attempt-at-being to enclose the other in its countenance: the other that is seen is threatened to be locked up in its visible form, its image (Levinas 1981:89-93). We indeed not only find this 'reduction of the other to the self' – the core of violence – in 'diagnostic reduction', but equally in other forms like indifference, instrumentalisation, domination and tyranny as expressions of the abuse of power, rhetoric, exclusion, racism, hate, murder ...: "so many ways of being comport a way of crushing the other" (Levinas 2001:53), slow and invisible killing, committed in our desires and vices, in all the innocent cruelties of natural life, in our indifference of 'good conscience' to what is far and what is near, even in the haughty obstinacy of our objectifying and our thematising, in all the consecrated injustices due to our atomic weight of individuals and the equilibrium of our social orders (Levinas 1994:110-111).

In the temptation itself to violence, however, according to Levinas, lies precisely the ethical significance of the face. At the moment that I am attracted by the naked face of the other to reduce the other to its countenance, I realise at the very same original moment that that which is possible is actually that which is not permitted. This is the core of the fundamental ethical experience that ensues from the face, namely the prohibition against imprisoning the other in its 'countenance' or visibility, or manipulating the other in one way or the other, or doing violence to the other. In my self-complacent attempt-at-being, which on the basis of observation and presentation wants to be wealthy as the expression and realisation of my own freedom, not only am I put in constraints from without but I am to my very depths – in the principle of my freedom itself – shocked and put to question. This is what Levinas calls the wordless word of the face, its ethical facial expression – something entirely different than its physiognomy: "You shall not kill" (Levinas 1987:55).

It is clear that according to the phenomenology sketched above, ethics – and thus caregiving as well – takes place as a shock-experience: the possibility and at the same time the prohibition against doing violence, or against functionalising, reducing or killing the other in one way or the other. This means according to Levinas that the ethical relationship with the other does not begin with positive norms of action that determine what we must do; it starts, on the contrary, with a negative intervention, namely a prohibition that questions the direct-and-spontaneous-movement of the observing and reducing attempt-at-being. Here ethics begins, in other words, as a form of fear or rather of 'shudder' (cf. Plato's idea of friké) (Levinas 1981:192). In the knowledge of my own attempt-at-being, knowledge that is aroused precisely by means of the appearance of the other, I fear that I will be violent and could kill the other. To kill should not be, as said above, understood here only in the strict sense of the word as the taking of life, but also in the broader sense as all forms of functionalising, abuse, subjugation, denial, forgetting, neglect, manipulation, intimidation, exclusion, of which killing is only the extreme, physical incarnation (Levinas 1998:244-245). This fear of killing is at the same time a fear of the other. Levinas expresses this original and foundational dimension of the responsibility-by-the-epiphany-of-the-other in a paradoxical manner by stating that the true ethical subject chooses to experience injustice rather than to commit injustice and that it fears less its own death than being the murderer of the other: the other literally "makes us tremble": "the fear of death is inverted into the fear of committing murder" (Levinas 1979:244). The fundamental ethical feeling manifests itself as a scruple. The Latin scrupulus

literally means a pebble in the shoe whereby someone cannot remain standing but is moved or induced to take a following step. Scruple is thus an unrest or shame or discomfort that inhibits: I am fearful of grasping and doing violence, of neglecting, of violating, of destroying, in short of 'killing' the other in its irreducible being-other that is at the same time its vulnerability whereby the other is delivered unto me.

We can also call this first ethical movement towards the other as a seemingly negative movement of restraint. Confronted with the vulnerable face of the other, I am called upon to restrain myself and to withdraw: an appeal towards circumspection and carefulness. Levinas (1999a: 125-126) literally says: "the apparently negative movement of restraint"; "be restrained in a quarrel" and "holding back the breath of naive life and thus awakening for the other" (Levinas 1999a:62). The ethical relationship towards the other begins as the paradox of 'restraint', shrinking or 'self-contraction' in the unashamedness and diligence with which our natural attempt-at-being moves forward without looking right or left, without care for the 'corpses' it leaves behind. Or put in a different way: the ethical relationship with the other begins as hesitation, as shame about oneself, as a movement of drawing back and questioning oneself: "What am I doing ...? Am I perhaps too 'violent', to self-assured and unconcerned, too careless or too paternalistically insistent, or am I only after my own happiness, future and meaning?" The appearance of the other touches and traumatises me into my flesh so that I do not feel good within me: ethics as the emotion of shudder that trembles throughout my body and feelings, and makes me uneasy (cf. supra Plato's frikè). Before ethics becomes a movement or an inspiration to do something for the other, it is first an inverted movement not to do something, namely to fall back on and shrink into oneself in order indeed not to take possession of the other or to treat the other disrespectfully (Levinas 1998:80-81).

Applied to the tension between 'countenance' and 'face' this means that the ethical relationship with the other begins as a self-contracting hesitation, namely as the carefulness and uneasiness to hold the other captive in an image – in our image. The other is no variant of me, no 'alter-ego' or 'other-I', thus no 're-issue' of myself. The other is 'otherwise' than me, and in that sense therefore an unknown, stronger, still an unrecognisable other: unsurpassable, infinitely otherwise than myself. The other is always more or less, or better still otherwise than the categories under which I can categorise, 'classify' or bring the other under a general denominator. In this regard – contrary to what common speech says – the first impression is not the best, but on the contrary the most dangerous and most misleading. Undoubtedly I am inclined to accommodate the other into my previously constructed – professional or otherwise – frame of reference but that which is possible is that which is not permitted. I must

restrain myself, relativise my diligence and obvious schemes and 'prejudices' (literally the judgements that I have already constructed beforehand) and at times even let go of them entirely. This requires acquiring an attitude of openness and receptivity, and thus also of vulnerability - the opposite of control and power (often built up on the pre-knowledge of expertise). Waiting and expecting, unbiased and attentive listening, suspicious towards one's own self-assured concepts and models, not seeking hastily for the confirmation of that which one has already 'believed' beforehand: this is what the encounter with the other is all about. To be alert for differences, ways in which the other 'deviates' from others – from the generalised other that I already have in my head: this is made concrete by the scruple which we discussed above. This must go hand in hand with a regular critical self-reflection – an examination of conscience - regarding one's own mode of approach towards the other, or else one lapses all to easily into the acquired and received patterns and images upon which one constructs one's own (professional or otherwise) selfcertainty and to which after a time – by force of habit – one becomes seriously accustomed and thus also maintains stubbornly. Only by means of this critical unease is the unique alterity of the other protected from all too great violence.

We likewise find this hesitation in the famous maxim by Kant on the human person. To approach the other as a person, in other words as an 'end' or 'value' in and of itself, does not begin after all in a positive manner that is clearly determined by content; it begins rather with not doing something, namely not treating the other as a mere means. We begin to treat the other as a person when we do not reduce him/her to an instrument or function of our own existence. It is only when we implement this diffident hesitation in our dealings with people that we are able to respect the other as other, i.e. as an intrinsic and irreducible value. In this regard, the Kantian concept of person is rather the expression of an ethical contrast experience than the description of a factual state. We constantly experience the risk of reducing people into a means for a certain goal. Its very possibility and the fear that we would take on this possibility makes us shirk in order not to debase the other into a thing or object - in order not to reduce the other into its (medical, familial, psychosocial, cultural) 'image'. Strictly speaking, the Kantian concept of person is a delimiting boundary concept that only sketches the conditions for treating human persons 'humanely', without saying something content-wise about what the being-person itself consists of.

Now the prohibition that nestles itself in me as a scruple, is only ethical in the strict sense of the word because the face of the other does not 'impose' itself upon me as a physical or moral force but as a demand that addresses me without forcing me. The ethical must is no natural necessity in the sense of not being able to do otherwise because one is surrendered to this or that

automatically operating causal mechanism. I can indeed surely kill, destroy or deny the other; I am not programmed 'to kill' or 'not to kill'; but I should simply not kill if I don't want to be 'inhuman' or don't want to act 'inhumanely'. The prohibition not to kill does not in any way make murder impossible, even if the authority of the prohibition remains present in one's bad conscience after having committed evil (Levinas 2006b:8-10).

Moreover, the ethical appeal that proceeds from the epiphany of the face also instigates freedom. Freedom no longer comes first but this does not mean that it would be unimportant. It is the condition of possibility for heteronomous responsibility to take place as an ethical event: it is the possibility of the response. In this regard, responsibility precedes freedom without destroying it; on the contrary, it bestows upon it a special calling, namely to take to heart the well-being of the other. We can synthesise this responsibility by means of the following paradox: 'in spite of myself, but not without myself'.

Ethical care relationship takes place as "for the other"

Now the apparent negative movement of restraint and circumspection opens up the space for the positive movement of the responsibility 'for the other'. We call it a responsibility in the second person because it starts from the second person, the other, and also directs itself towards the other (cf. indicated above as 'heteronomous responsibility'). It is not only about not killing the other nor doing it any harm, but also that justice be done to the unique beingother of the other so that he or she can truly be. We can also simply call this the ethical foundation of caregiving, whatever the methodologies and paths may be that certain 'schools' or particular 'sectors' apply according to their own discoveries and insights. Letting the other truly come to be implies that one acknowledges, respects and promotes the irreducible alterity of the other. Concretely speaking, this means that one makes an effort to overcome the asymmetrical power relationship that lies within every caregiving – by the fact alone that the caregiver has jargon at one's disposal within which the needs of the care-seeker or suffering other are expressed. The strength of Levinas' view is that he completely reverses the asymmetry in the sense that the caregiver stands in service of those who seek care or are in need. The care-seeking other stands 'above' the caregiver in the sense that the latter directs oneself to the other in need and obeys the other - literally "to give ear" to the appeal that ensues from the vulnerable and hurt face of the other. It is not I – as caregiver - who is the authority, but the other who is my 'lord and master' - the elevated Thou – who instils respect in me. Here the traditional perspective on caregiving is turned around in the sense that it is not the caregiver who comes first but the 'other', the 'care-seeker'. And thus listening comes before speaking and 'responding'. Caregivers are 'responsive' and 'answering' beings!

This all means therefore that the responsibility for the other of the caregiver must be examined attentively. It shows indeed a remarkable paradox. From the 'I' - the caregiver - it stands entirely directed towards the other. And that which this responsible care aims at is the well-being of the other, as was already mentioned. In Levinas we find precisely the paradox that the highest spiritualism, namely the responsibility by and for the other as the dynamism of self-transcendence, is at the same time the highest 'materialism'. The care for the other must namely be incarnated in, and concretely be in tune with, the needs of that other. The other as 'other' appears to me as an appeal insofar as the other is 'in need', destitute or sick, a creature of suffering and morality. The hunger of someone else – fleshly hunger, hunger for bread, and mutatis mutandis need for clothing, housing, care, healing, asylum, advice, assistance, and so on - is holy (Levinas 1990:XIV). I cannot come to the other emptyhanded; that would be a vain and sanctimonious gesture. The 'need' of the other demands that we instigate all means and 'discoveries' of a scientific and technical nature for the other's healing, care and well-being. In this sense, not only caregiving but also medicine has an ethical meaning and foundation.

Is not the evil of suffering – extreme passivity, helplessness, abandonment and solitude – also the unassumable, whence the possibility of a half opening, and, more precisely, the half opening that the moan, a cry, a groan or a sigh slips through – the original call for aid, for curative help, help from the other me whose alterity, whose exteriority promises salvation? Original opening toward merciful care, the point of which – through a demand for analgesia, more pressing, more urgent, in the groan, than a demand for consolation of the postponement of death – the anthropological of the medical, a category that is primordial, irreducible and ethical, imposes itself. It is seen in the light of such situations, that medicine as technique, and consequently the technology as a whole that it presupposes – technology so easily exposed to the attacks of 'right-thinking' rigor – does not derive solely from the so-called 'will to power.' That bad will is perhaps only the price that must sometimes be paid by the high-mindedness of a civilization called upon to feed human beings and to lighten their sufferings (Levinas 2006b:80).

Our entire earthly spirituality consists in nothing else than the material gesture of 'assistance' to those who literally are 'in-need-of-care', of seeking for a very concrete and adequate response to the other's needs, on the basis of an appraisal of the other's cry or request for help – medical assistance and caring – that is as honest and adequate as can be. The relationship with the other does not take place outside of the world like a sort of blissful beholding of the other's alterity or 'mystery', but only in and through the world. The yes-word of the responsibility taken up for the other must literally 'become flesh' in the hands that give, in the body that takes concrete steps and does

tangible things. Care for the other implies necessarily the objective or concrete deed of my 'work' (Levinas 2006a:25-29): it is after all about a tangible commitment and a concrete 'practicality in-deed'. The care for the being and well-being of the other cannot in any way whatsoever be content with some well-intended compassion or good intentions alone. Whoever takes up one's responsibility for the other must take seriously the 'worldly' needs and cares of the other. Responsibility is the paradoxical relationship with the other as an involvement in the other's alterity, which is at the same time an involvement in the other's 'being', including all the shortcomings, sufferings and injuries of this being: 'the positivity of an attachment to being as the being of the other' (Levinas 2009:122). This concretely means that a responsible caregiving must commit itself to understand correctly the appeal that ensues from the vulnerable and injured face of the other, without imposing one's own prejudices and prefabricated schemes. Attention and care for the other in need implies that the caregiver time and again must question him/herself about what the true appeal of the face is, and thus what the possible question is that lies behind the question. Which suffering or problem is expressed or hidden in the question posed? What is the real need that lies hidden beneath the hesitation or nervousness, beneath the timid or closed, or conversely insistent, face, beneath the specific body language? These and other 'searching' and 'probing' questions express how the caregiver is concerned with the concrete being and well-being of the other.

From the 'infinitising' of this 'materialism' of responsibility-for-the-being-ofthe-other, Levinas states that the highest form of responsibility consists in not abandoning the suffering and dying other to his/her fate. The fear for the mortal and dying other is even the ultimate foundation of responsibility. I am so moved by the death of the other that I hold myself responsible for the extreme violence that the other, precisely through its mortality, must suffer. The unease that the appearance of the other arouses in me is the care for the other in the 'e-norm-ous' vulnerability of its 'passivity' and being delivered unto death: 'entry into the concern-for-the-death-of-the-other' (Levinas 1998:164). Concretely speaking, I am obliged not to leave the other when he/she - as a result of an accident, suffering or debilitation - is confronted with death, even though I am powerless against this relentless, ultimate enemy and I can only but respond with the meagre 'here I am' of a lingering and caring nearness, that holds the hand of the other. Eye to eye with the death of the other, the true and pure goodness 'without desire nor interest' appears: a nonindifference par excellence, that desires in no way whatsoever any reward for oneself, a non-reciprocal goodness that even bears to be vain and futile over and against the ineluctability of death. On this basis, we even dare to formulate a new categorical imperative, namely that no person should be allowed to die alone. What we mean with 'alone' here is certainly that no dying person should be abandoned to his/her lot. But we also dare understand it in a stricter sense, in the sense that no one should be allowed to die literally alone, even when the other can do nothing more (Levinas 1985:119). (See Chapter 6 for a similar discussion.)

Responsible for the responsibility of the suffering other

With this, however, not everything has already been said about the responsibility of the caregiver for the other. With Levinas we would like to take a step further, namely that the responsibility of the caregiver is likewise a "responsibility for the responsibility of the other" (Levinas 1981:117). We can distinguish two aspects therein: on the one hand, the care for the responsibility of the other for oneself and, on the other hand, the care for the responsibility of the other for others.

The paradox of all caregiving is that as 'altro-centric' – i.e. directed towards the other – responsibility it cares for the self-responsibility of the other. We can call that the emancipatory aspect of care. Care for people in need of care must see to it that it does not become a meddling care, or that it cares for the other so much so that the other is prevented from caring for him/herself. One of the goals of caregiving, therefore, is that the ones in need of care are enabled again, to the extent that this is possible – to care for themselves: to take care that the other can arrive at self-care. As the 'recipient' of care, the other should not be reduced to a mere passive 'object', unless it cannot be otherwise. The care for the other should not be perverted into a way of approaching the other 'paternalistically' so much so that the other is alienated from its 'being-self'. In this regard the caregiver is faced with the responsibility to likewise 'withdraw' him/herself in his/her care for the other, in other words, to create space for the restoration and promotion of the free responsibility of the one in need of care for him/herself, at least as much as possible (for we cannot forget the fragility and the incapacity of the care-seeker, of which the small vices of mediocrity, hypocrisy, laziness are particular expressions).

Upon closer inspection this emancipatory dimension of caregiving, however, also has its reverse side. Indeed in the description of the ethical structure and modality of caregiving as responsibility for the other, it is important to be aware of the effect of this responsibility on the other, the one in need of care or the care-seeker. If as caregiver one does not pay attention to that, this can give rise to pernicious anomalies so that even that responsibility by and for the other can be turned into its own antithesis. Then evil will flow forth from the good. In the concrete, applied level the question indeed is not only what this responsibility is and means for the responsible caregiver,

but also where this responsibility leads or should lead. If we do not pose this second question, then it is very possible that in our care for the other, with all possible commitment and dedication, we end up with an egocentric result in the care-seeker. The responsibility taken up can be very altro-centric and unselfish but this can imply that the care-seeker is led to a bourgeois, selfcomplacent life wherein only the care for oneself is important. To state this in a paradoxical manner, the altruism of the one can directly lead to a promotion of the egoism of the other, even when the caregiving is not so much directed at relieving this or that need but rather at empowerment or the strengthening of the personal, social and cultural growth of people. The dedication of the one can bring forth the profiteering of the other. Naturally in caregiving one is responsible for the promotion of the self-responsibility of the other, both when the freedom that forms its foundation is not present or is insufficiently present as well as when the free self-determination must be strengthened in its development (cf. supra). But the responsibility of the caregiver must go further: it must become the responsibility for the responsibility of the other, to be understood as the responsibility of the other for others. In other words it is not only important to emphasise the responsibility of the caregiver for the other, but likewise to draw attention in the case of the care-seeker to the importance of his/her responsibility for the other. Caregiving is faced with the task of taking up the responsibility for the other in such a way that the other is supported and stimulated to also acknowledge, take up and develop his/her heteronomous responsibility by and for the other. If this does not happen caregiving will come to stand in contradiction with itself, and even come to destroy its own dynamism and meaning: out of an extreme attention to the other, the other is then only led to putting him/herself in the centre at the cost of others. Concretely speaking, for caregiving this implies that, if necessary, the care-seeker is also confronted with a number of boundary rules of which "you shall not kill" remains the absolute boundary rule. "Do no harm" is a fundamental condition for human social life and the creative development of the responsibility for others, both individual as well as social. The responsibility of the caregiver for the emancipation and empowerment of people must also be concerned with developing and strengthening their inter-human and social responsibility, if possible.

Of course this must take place with the necessary circumspection. Perhaps one will not start with this confrontation since one needs to meet the needs and necessities of the care-seekers. The ethical dimension of the responsibility for the other should not in principle be excluded, but needs to be introduced into the caregiving process. And this is not non-committal. It is not about a possible, optional possibility that is just as well negligible. On the contrary, it is about an essential dimension of the 'person adequately and integrally considered'. People can be 'sick' of too much ethics (sense of responsibility

and guilt), but they can also be 'sick' of too little ethics. The caregiver that desires to empower people so that they can face the world again out of their own strength, cannot empower people to just anything whatsoever. In his/her work the caregiver must confront the persons with whom he/she works with the boundary rule 'you shall not kill', expressed in 'do no harm.' The caregiver must state clearly that empowerment can never mean excluding others or self-development at the cost of others.

Caring for the many others (responsibility in the third person)

Once again, not everything has already been said about the responsibility by and for the other, and thus about caregiving as well. In the thought of Levinas lies an unambiguous social and political dimension as well, although this is at times overlooked or minimised (Levinas 2009:122-123).

Ethical appeal to just caregiving

We start from the very primary observation which Levinas likewise does in his phenomenology of the 'face-to-face', the direct "other-I-relationship". The other and I are indeed not alone in the world. We are not only a duo, but also a trio: there is the third, the fourth, the hundredth, the thousandth, the millionth. This is still merely quantitatively considered, however. The idea of the others in plural should also and especially be understood qualitatively, namely as those who in the face-à-face are not present immediately but at most in the side-lines. Even when they are materially not within the immediate vicinity, they are at the same time 'removed'. Most others are moreover also materially absent and even 'far away', which Levinas also calls the "far ones". To indicate all these absent, removed others, Levinas uses the term "the third" or "the third party" (le tiers) (Levinas 1981:16) and he refers to the grammatical third person: "he/she", both singular and plural. The 'third person' is precisely the one with whom I cannot stand eye-toeye because he/she is absent. I cannot point to the third directly, just as I can point to myself as 'I' and to the other before me as 'you'. I can only refer to the third by means of pointing away from myself and the other, and towards a 'yonder', an 'ille', with whom I cannot enter into contact directly unless I reduce the presently present other into the third. That is why Levinas justifiably uses the term 'illeïty' to evoke the specific status of the third. In short, the third is not the unique, irreducible other that by means of its face demands me to say 'you' or 'thou' but rather he/she is the one who comes 'from elsewhere' and lies out of sight or disappears from our view (Levinas 1981:157-158; 1998:82-84).

And yet we cannot say that the third parties do not concern us, that we have nothing to do with them. They indeed play a non-arbitrary role in our direct other-I-relationship, which Levinas calls a "true society" (Levinas 2006b:17), in contrast with the intimate, closed 'I-you-relationship' against which the others as spoilsports are kept out. This interference by the 'third' is concretely apparent in the injustice that is already immediately interwoven in the other-lrelationship, and this not on the basis of this or that bad intention but on the basis of the eye-to-eye itself. When I comply completely with the appeal of the face, and thus become the unique responsible one for the unique other, which is actually my duty, then I necessarily do injustice to the absent thirds. When I do everything for the one other, then I forget the absent third and I also do them injustice. By only listening to the needs or the problems of the one, unique other, I do not listen to the story of the absent third to whom the other also stands in relation nonetheless. This is the tragedy of goodness: when I turn myself to the one other, I unavoidably turn away from the others. In the face-à-face, in other words, there are always absent ones, excluded ones, which leads Levinas to speak about the first, unavoidable violence of goodness (Levinas 2001:55-56).

In any case it becomes apparent here that our responsibility reaches farther than the unique other, with whom we are directly confronted. It is involved at the same time with the thirds who are easily forgotten but – ethically speaking – should not be forgotten. In principle no one should be excluded from this extension to the others in the plural for then we would undermine the universal character of the categorical imperative and furthermore move to make 'selections' of those who would fall under our ethical care and thus would be considered as 'humans'. These selections could only rest on arbitrariness which would immediately lead to racism with its double idea of preference and exclusion. That is why the responsibility in the third person acquires a universal scope (Levinas 1981:116-117).

The extension of this responsibility for everyone, without exclusives or prerogatives, needs to start, however, as a remediation of the initial violence that lies within the *face-a-face*. This is only possible when goodness becomes justice. As long as responsibility only runs from me to the one other, it has a univocal and 'mono-fold' meaning. But starting from the entrance of the third the question arises: "Who is most near to me? Who comes first: the second person or the third?" The third is just as much my 'other' as the first near other. At the same time the other and the third also have their 'others', meaning to say their near ones and thirds. Well then, this conflict in responsibility itself evokes the necessity to confront and to judge, to weigh and consider, to arrange and organise. Our responsibility that reaches farther than the unique other, towards everyone, both near and far, obliges us to take all others into account.

We must compare and bring together, classify and deliberate; in short, we must 'moderate'. And this 'comparing' must take place as much as possible in a fair and balanced, in short, just manner: "the hour of justice" (Levinas 2006b:198).

The fact is that the 'human plural' indeed has implications for our view on caregiving, in the sense that the *face-à-face-caregiving* gets stuck in an abstraction or even in an ethical mistake if it loses sight of the relationships with the thirds.

First and foremost, in all caregiving (both from the individual caregiver as well as the society, namely the government) the responsibility in the second person needs to be corrected. The care for the one, unique other must be lifted out of its abstraction. In the care for the other, in other words, we are faced with the ethical task of taking into account his or her 'vicissitudes' in the social network, otherwise we do injustice to the other and he or she is not approached integrally and adequately.

Moreover, the caregiver should not segregate him/herself with the care-seeker in order to bear responsibility only for that one, unique other. The absent thirds also fall under the responsibility of the caregiver – to be understood as an individual or as a 'service' (an institution). One needs to take into account the consequences in both short and especially long term, on an inter-individual and especially social level, of the actions of caregiving. Caregiving, in other words, cannot limit itself to an inter-individual approach but should also involve the relational and social network, for instance the family and the neighbourhood, in the giving of care as belonging essentially to that caregiving. A caregiver cannot hide behind the argument that one has too much work or that the case load is too high or that one cannot change. Our fixation on an individual client and its context out of good intentions can become a perversion of the good because injustice is done to others whom we have not yet seen by means of our not reaching out to them. That is why caregivers – and the organisations wherein they work - must question structures and challenge policymakers because there will always be unique others who are not seen, who do not receive care, who are not able to achieve their dignity and (manifold) responsibility and whose appeal is not 'noticed' or heard by the caregiver. This requires creativity, courage and deliberation.

Ethical appeal to organised caregiving

There is more, however. Since we cannot directly reach most third persons, we must realise justice by means of 'mediations' (*Vermittlungen*). We can only concretely substantiate our care for the third when we introduce 'intermediaries' between ourselves and the absent ones whereby we reach them only indirectly but still really: in any case we are able to do something for them. These intermediaries

are all sorts of forms of structures, laws, institutions, organisations, professional bodies and systems, and this both on the economic, social, juridical as well as political levels, both infra-national as well as national, international and global. Levinas calls this the 'state' or 'polis', or even 'the political' in the broad sense of the word (cf. Aristotle). On the different levels of this structural mediation and formation, informed and unbiased governments are needed that not only represent and coordinate the socio-economic or political order but also execute the needed policy. Without the extension of just laws, intermediary organisations and societal structures, we commit desertion with regard to our responsibility for the others in plural, and ultimately for humanity (Levinas 1979:300; 1981:157-158).

Due to the involvement with the 'third', caregiving actions should thus surpass the direct other-I-relationship towards a social, institutional, organisational and structural mediation of care. This can then make possible and guide a balanced and just division of forms and modalities of care, as well as financial means. Here the various individuals and governments responsible for social and political matters have an essentially regulating role to play, out of the ethical task to promote a just general welfare. Here we would also like to emphasise the responsibility for the caregivers themselves. From the responsibility in the third person, policy bodies of the various social levels are indeed faced with the task of creating the necessary legal, structural and organisational provisions and forms of guidance also for the caregivers. This is not only to allow organised caregiving to function as efficiently and professionally as possible, but likewise out of respect for the caregivers themselves. As human persons, they indeed have not only duties and tasks but also rights, which must be taken to heart by the society and its appropriate social organisations.

Ethical alertness relative to organised caregiving

There is a negative reverse side, however, to all social and political forms of our universal responsibility, however ethically necessary they may be (Levinas 1996:23), and this is that they can never have the final word. The state and society, however, are constantly in danger of being degraded. Since they take shape in laws, structures, organisations and institutions, for instance in education, healthcare and welfare, or in financial systems (of subsidy, among others), they inadvertently show an objective, distant and anonymous character. Their nameless objectivity lies as the cause of why subjects are not really treated as separate persons but rather as elements that are conceived of by means of a generalised denominator or totality in terms of their function, status, profession, studies, possessions and property, ideology or religion. In this sense the objective generalisation, which the socio-political order in society must carry out in order to substantiate its task of justice for all, also for the thirds, signifies the constant threat of structural violence and tyranny that deprives individuals

of their irreducible separateness and alterity (Levinas 2001:68). Here we touch upon the drama of all social, economic, legal and political organised justice that nonetheless finds its origin in the ethical appeal of the face of the other, namely by turning against this face (Levinas 1979:16, 276).

For this reason no single social, economic and political order should have the final word. A totalitarian regime is precisely such an order that has elevated itself into a definitive regime. In the 20th century, Stalinism has made clear how nefarious such a regime can be, especially when it then still appeals to the ethical care of the proletariat. Stalinism is, in other words, the terror of the perversion of one's own ethical compassion (Levinas 2001:81). Put differently, Stalinism inadvertently turned against its own original 'good will', precisely because it absolutized its choice for the vulnerable other into an all-encompassing and final system or a 'final totality'. This is the worst that can happen to ethics, namely that in the name of the other a socio-economic and political system is created and even proclaimed as the absolute good. The good is turned literally into "the evil of the good" and thus ends up as the "terror of the good" whereby ethics itself is destroyed in the name of ethics (Levinas 2006b:199).

This indeed likewise applies to organised caregiving. Precisely out of the ethical foundation of institutional and structural developed caregiving, we should not lose sight of the possibility of perversion that is inherent in structural forms. In order to avoid all totalising and even 'Stalinist-style' petrification as a consequence of the objective, generalised and conservative character of institutions, legal regulations and organisational forms, ethical alertness is necessary in order to question existing structures as to their function and goals time and time again. Existing, socially organised and politically directed caregiving should never have the final word (Levinas 2006b:167-168).

Ethical levers in organised caregiving

As a result, social, economic and political realisations – and by extension, the organised provisions with their legal frameworks – must always be questioned and surpassed on the basis of their original ethical inspiration, namely the considerate responsibility by and for the other. Hence, even on the structural and organisational levels, the input of the *face-à-face* and the responsibility-by-and-for-the-other are indispensable as levers and inspiration.

First and foremost, a questioning and surpassing are needed by means of "an even better justice" (Levinas 1998:9). The options, priorities and achieved balances that are secured in organised caregiving, create ever new injustices. Consequently, an even better social, economic and political justice is needed as a critical corrective that tries very attentively to identify, prevent or remedy every degeneration of structural socio-economic and political justice. This is

only possible in a non-totalitarian, 'free', regime that takes as its principal starting point that the justice attained is always incomplete. The justice attained is never just enough and every new justice creates still more new injustices that in their turn require adjustment or even radical renewal. This applies in an eminent way to the provisions and organisations that concentrate on one form or the other of caregiving.

The dynamism of an even better justice arises, according to Levinas, by creating space for human rights that take to heart in their pure, non-political formulations the rights of the other over and against every 'state' and every socio-political system (Levinas 2001:68-69). It should be noted how well Levinas puts emphasis on the rights of the other: for him, the rights of human persons are pre-eminently the rights of the unique other (Levinas 1999b:149) – and it is precisely these rights that call us to responsibility for that other. With human rights, which per definition never coincide with a justice regime, we can question radically or shatter a petrified socio-political care system towards greater justice. Human rights have, at the same time, a critical and prophetic character. They go against all resignation and self-validating conservatism and provoke or literally call people forward to strive for true justice, without lapsing however into the perversion of a totalitarian justice system (Levinas 1993:123).

Aside from this "permanent social, economic and political sobering", Levinas also argues for what he calls "ethical individualism" (Levinas 1996:24) - which also applies to the care system that has developed in our society. By this he means the irreplaceable role that the interpersonal responsibility of the 'onefor-the-other' has to play in just structures, institutions and (care) provisions. There are, if you will, tears that no single functionary of whichever socio-political or care system can see, namely the tears of the one, unique other. Well then, so that things would work properly and run in a humane manner, the singular responsibility of everyone, for everyone, towards everyone, is and remains - above every system - necessary. In every socio-economic organisation, in every political order, in every care system, individual consciences are needed that unconditionally take upon themselves the fate and well-being of singular, unique others. They alone are capable of seeing the violence that ensues from the good functioning of the 'social and political rationality' itself, even of organised, legally regulated and socially subsidised structures and organisations of care (Levinas 1996:23).

In this regard, Levinas speaks of the ethical necessity of the "small goodness" (Levinas 2006b:199). He calls it small because it runs from the one to the unique other, because it does what no system can ultimately do, namely address the needs of the singular other with concrete compensations. Small is this goodness as well because it is anything but spectacular and neither does it intend to be total. It is about a modest, partial goodness that has no

pretence to solve everything at once and for all time, and thus create paradise on earth. With full enthusiasm and dedication, it does what it can, without desiring to have everything in its grasp. This humility can also be called the frugality of goodness that is aware of its own vulnerability but does not for that reason throw in the towel cynically or in defeatism (see Chapter 3).

This "small goodness" can be concretised on the basis of Levinas' idea of "noble casuistry" (Levinas 1982:121-122). As the incarnation of the responsibility of the one for the other, this casuistry strives to let the separate 'case' come to its own without having the pretence of achieving the 'final solution' for all problems of all possible cries for help. The value of this casuistry well understood consists in that it constantly takes the unique other into consideration, with the concrete situation of each *casus*. Or rather, it approaches people and situations not as particularised, exemplary applications of general principles, but in their irreducible and unrepeatable uniqueness, as 'separate cases'. It rests on the acknowledgement of the fact that a being stands before me that is utterly new or *hapax*: someone who is only once, here and now.

In this regard, noble casuistry is an eminent precautionary measure against all forms of ideology and reduction that makes of the singular case only a concrete application of the general principle or of a legal, globalised regulation – such is bad casuistry as it often traditionally functioned.

It is indeed for that reason that conscientious, individual caregivers are needed precisely in a structurally and organisationally well-extended care system. In their fleshly affectivity they are sensitive and vulnerable to the suffering and need of the separate, unique others. And thus they both intercept and correct, and thereby question, the unavoidable shortcomings of all social, economic, juridical and political provisions and care services. They are the "lungs" through which organised caregiving keeps on breathing, without it implying a guarantee of a perfect care system in the future. Neither in ethics nor in caregiving does an eschatology exist, i.e. a certain, total and definitive conquering by the good (a perfect care). Everything still remains to be done time and time again, and this by unique people who take upon themselves the fate and well-being of unique, concrete others. This is and remains the ethical ground of all organised caregiving, today and tomorrow.

The touchable face of the caregiver

There is one aspect of the responsibility of caregivers which we have up till now not yet clarified, namely an aspect that has to do with the view of the caregiver as a human person, or rather with the underlying image of the human that is implied and supported by the entire developed view on caregiving. In the last part of this philosophical postscript, we now would like to reflect on the matter of 'sensibility' as further elaboration of this idea that is brought on at the end of Chapter 1.

Upon closer inspection, the description of our responsibility by and for the other, the ethical core and dynamism of caregiving, brings us to a re-definition of the human subject, namely as "being-for-the-other" and thus as rooted in our human condition as "solidarity and brotherhood" (Levinas 1981:8-11, 14-15, 17-19).

All that we have mentioned above about the face of the other that calls me – a human person, a caregiver – to responsibility and goodness can only be posited if we correct the description of the 'I' as 'struggle for life' (on the basis of a flexible capacity for adaptation – Darwin), or as "attempt-atbeing" (conatus essendi – Spinoza). Upon closer inspection, it indeed becomes apparent how the determination of the 'I' as attempt-at-being is literally too superficial, meaning to say it remains at the surface and does not do justice to that which takes place, or rather has already taken place, in the 'depths' – in the intimacy – of the 'I'. The preliminary determination of the human person as 'interestedness' is too one-sided and does not do justice to the integral 'human condition'.

In order to clarify what we mean by this, we must return to our description of the ethical encounter with the face of the other. We have described this encounter as the heteronomous event of being touched by the vulnerable and suffering or injured face of the other. We are literally 'affected' and touched by the epiphany of the other, so much so that we cannot remain indifferent anymore. In spite of ourselves, we are called by the naked face of the other, literally summoned to responsibility. In order then to be able to be touched by the fate and suffering of the other, we must be touchable. So that that which happens can happen, namely the 'hetero-affection' by the face, we must suppose that we are 'affectable'. Here, we clearly move from a phenomenological, descriptive level to a transcendental level in the Kantian sense of the word: in the depths of the phenomenon we begin to search for its condition of possibility. Even before I take up the responsibility for the other, I must already be responsible in my being. In this regard, Levinas draws attention to the suffix of the French word 'responsabilité': 'bilité' in fact refers to the possibility of giving a response, to the being enabled to be able to respond effectively to the face of the other. Even before I attune myself to the 'slings and arrows of outrageous fortune' of the other, I am already – in spite of myself, thus in my very being – attuned to the other. I am entrusted to the other, beyond my own initiative, and thereby I am 'made capable' – literally 'constituted' – of dedicating myself to the fate of the other. In the heteronomous responsibility, I discover in other words myself as already marked by an event that precedes me in a radical manner. In

order to know my true ground, I must return – back to an immemorial past – to before or under 'my-self'. This being affected passively by the fate of the other is the very intrigue of my subjectivity: movedness in spite of myself, 'animation' and 'inspiration', in the sense of 'being ensouled and inspired' by the other than myself. Responsibility through the naked face does not remain exterior to me but takes place in me, or rather has already taken place within me as an 'awakening' ('éveil'), or stronger still as an 'already being awakened' ('déjà être 'éveillé) to responsibility, which I then naturally must take up and substantiate by myself in freedom (Levinas 1998:23-26).

The condition for, or the unconditionality of, the self does not begin in the auto-affection of a sovereign ego that would be, after the event, 'compassionate' for another. Quite the contrary: the uniqueness of the responsible ego is possible only in being obsessed by another, in the trauma suffered prior to any auto-identification, in an unrepresentable before. The one affected by the other is an anarchic trauma, or an inspiration of the one by the other, and not a causality striking mechanically a matter subject to its energy. In this trauma the Good reabsorbs, or redeems, the violence of non-freedom. Responsibility is what first enables one to catch sight of and conceive of value.

- Levinas 1981:123

This requires redefinition of the 'I' that we initially, surely in this present neoliberal climate, spontaneously or obviously characterise as 'self-interest' ('intéressement') that marks our free striving for autonomy. This description of the 'I' as 'being' on the basis of what simply seems to be evident in our daily observation is too flat in the sense that it concerns a half, and thus incorrect, truth (a half truth is more dangerous because it is more misleading than a whole lie). On the basis of the questioning regarding that which makes possible the factual being touched by the face, namely the touchableness of the 'I', Levinas arrives at the statement – especially in his second major work Otherwise than Being (1981) – that the being of the 'I' is not simply being, but in its 'being' is already an 'otherwise than being'. As a being that is concerned about its own 'being', the 'I' in its being is already marked by 'the other than its own being'. According to Levinas – and here we stumble upon the true origin of his ethical thought – we have neglected something essential in the (current, unthought-of) characterisation of the 'I' as self-interest and attemptat-being, namely 'something' that is already at work in the attempt-at-being itself (Levinas 1981:102-109). Concretely in the attempt-at-being itself, in the same and not outside of it, there is a scruple at work that questions the conatus essendi from within and breaks it open towards the other than itself. 'Scruple' literally means a 'pebble in the shoe' whereby someone cannot remain

standing but is 'moved' or 'impelled' to take a next step. Levinas thus speaks, and not coincidentally, about "the other in the same" - "the explosion of the other in the same" (Levinas 1998:29). This scruple that touches the attemptat-being itself comes to light through the encounter with the face but is not installed nor created by this encounter. The scruple about oneself that is at work in the conatus essendi itself from within and by means of which the 'I' is already connected to the other than itself, manifests itself however as an ethical event. The involvement with the other than itself is no 'necessity of nature', just as indeed even the attempt-at-being is no 'necessity of nature', in the sense that the human person cannot but choose for the other or for oneself. The 'dedication in spite of myself to the other than myself' takes place precisely as a scruple, as a questioning, as a discontent of the attempt-at-being about itself. As conatus essendi I am uneasy about my own dynamism-of-being, I realise that the obviousness of my perseverance-in-being and self-unfolding is entirely not so obvious, that I may not simply live out my self-interest. In the exercise of my attempt-at-being, it finally dawns upon me that my attempt-atbeing that is left to itself is brutal and leaves behind trails of corpses left and right. Even though there is a certain 'natural urge or inclination' in the conatus essendi to think and act according to its own interest, it still is not surrendered to itself as an inevitable mechanism that is a necessity of nature. Precisely because it is marked by an internal scruple or restraint about itself, it is ethical whereby it surpasses nature – understood as 'law of nature'. By means of the crisis that it brings along with itself – 'the crisis of being' – it is not surrendered to itself as a fatality but it can surpass itself towards the other than itself. By means of the internal scruple it is enabled to choose for self-interest or choose for the 'otherwise than being' whereby it surpasses itself as an 'involvement in the other than itself'. But then again, this does not mean that this 'otherwise than being' would be an ontological necessity or a natural phenomenon. The 'I' is not surrendered irresistibly to its 'being' nor to its 'otherwise-thanbeing'. It can simply choose to be and to live out its self-interest at the cost of or in compromise with others, but it can also choose to authenticate its otherwise-than-being in caring responsibility for the other both in the singular - interpersonal - as well in the plural - social, economic and political, national, international and global. In this regard, the 'I' is an ethically 'equi-vocal' being: being and otherwise-than-being at the same time, without it having to fall in one or the other direction like a stone that unavoidably falls downwards ... or upwards (Levinas 2006a:52-55).

In this manner the attempt-at-being is itself already marked and 'touched' by the "otherwise than being" or "the Good beyond being", not as an unavoidable necessity but as a condition that means at the same time being addressable. It is not for nothing that Levinas labels this as "the very miracle of the human in being" (Levinas 2001:111): the other in the same, transcendence in immanence,

the 'extra-ordinary' in the 'ordinary', or expressed figuratively: the ethical motherhood of "having-the-other-in-one's-skin", "bearing par excellence" or "gestation of the other in the same" (Levinas 1981:75, 115). Levinas likewise calls this 'incarnation' the human condition of 'sensibility', a passive sensitivity that is bodily through and through: being touchable in spite of myself, or stronger still being "already touchable" even before I am touched, preceding entirely the active "my letting myself be touched" (see also the end of Chapter 1). In the heteronomous passivity of sensibility that is marked by a passivity that is more radical than all intentional passivity, our body reveals itself as our soul: "psyche as maternal body" (Levinas 1981:71). We bear the other already in our bodies whereby we receive the other to be borne: our body is ethically ensouled, it bears an ethical signature in itself that already since time immemorial – before all possible memory – is etched indelibly (Levinas 1981:89). In and through my sensitive and vulnerable body I am already connected to the other, even before I can connect and identify myself with my body as 'my' body (Levinas 1981:76).

In this regard the Good reveals itself in my bodily, earthly being itself, not in the active consciousness of myself as 'interest', but deeper than this consciousness in my 'soul' wherein 'in spite of myself' I am ensouled towards the other. Here we touch upon the soul of the 'I', namely the ensoulment and inspiration by means of the radical other (Levinas 1998:32). And this 'being for the other in spite of myself' implies that the 'I' no longer stands in the nominative but in the accusative just like it apparently is in the French expression: 'me voici'. In contrast to the English expression 'here I am', whereby the 'I' stands in the active nominative, in 'me voici' we have the 'I' in the passive accusative which means in a grammatical form for which no nominative form even exists (just as is the case in the Hebrew word Hineni). In spite of myself, I already stand before every choice I make – under the command of the face whereby I discover myself as that which is already called 'from elsewhere'. I am already a passive 'me' even before I can become an active 'I'. In this regard Levinas speaks also about the createdness of the ethical subject, a form of ethical "Geworfenheit" ("thrownness") (to make use of a Heideggerian term and to recalibrate it ethically). I am created as "my brother's keeper" even before I would be able to have any idea, desire or intention to want to be such a keeper. Upon closer inspection, Cain's question: "Am I my brother's keeper?" (Genesis 4:9) reveals the "prehistory of me as responsibility", namely a being held responsible in spite of myself for the other: the condition for and the soul of all solidarity with others, close by and far away, today and in the future (Levinas 1981:117).

This implies the suggestion to turn around the order of the trio of the French Revolution from "freedom, equality, fraternity" to "fraternity, equality, freedom". In our being we are so connected to each other that we stand facing towards each other as brothers who are held responsible for each other and thus need to care

for each other. This 'covenant' not only precedes but also forms the foundation of all 'contract' between people. Without the universal 'connectedness in fate' with all people in spite of ourselves, whereby we come to bear the fate and the care for the being and well-being of others, there would simply be no caregiving possible. It is precisely by means of the 'connectedness in fate' – fraternity – in which we 'find' ourselves that thus precedes our freedom and is literally our 'soul', that we are 'ensouled' and 'driven' to bear the other in its need, suffering and guilt, and to bear this up to the extent that the other is then able to bear itself and others as well. The "soul within my soul", the ensoulment by the other than myself makes my heart beat for the other: thus the other is the heartbeat of the same (Levinas 1998:24-25).

A story about protesting angels

To conclude we would like to retell in our own manner and interpret an ancient Talmudic apologue that Levinas cites (Levinas 1993:39), in order to express evocatively once again the fundamental relational and bodily dynamism of the multi-vocal care responsibility to which the human person is 'created and called'.

One day the angels in heaven found out that God in His unfathomable wisdom wanted to entrust the *Tora* or the Law to humans. Not only were the angels surprised, they were also perturbed. They did not understand why God ignored them and turned to beings of a lower status. Thus they organised a protest march to prevent the *Tora* from leaving heaven. With the archangels leading them they set forth to meet the Lord, who had already seen them approaching from afar.

When the angels arrived they questioned the Lord. In their opinion, He had to justify Himself for His choice, which to them seemed more foolish than wise. And the Lord seemed prepared to tell them why He wanted to give the *Tora* to humans, on condition, however, that the angels first answered His counter question: "Do you work by the sweat of your brow for your daily bread?" The angels looked at each other for they actually did not understand what the Lord was asking about. To save face, they decided not to answer. Then likewise did the Lord not answer their question and He withdrew back into hiddenness.

After a time, however, God was overcome with sadness for He did want to shed light on His decision. Thus He posed a second question to the angels: "Do you buy and sell?" The angels were shocked for they had heard of machinations, corruption and abuse of power that arise because of money – dirty money! – amongst people. But because they only knew about this from hearsay, they did not dare answer. And again God withheld His answer. He again withdrew until

it became too much for Him again, for He does not shield His wisdom in fear and jealousy from His creatures.

Since all good things exist in threes, He decided to give the angels a third chance. His new question then went: "Do you bear children?" The angels were even more scandalised by this question than by the former. The stories of humans and sex – and everything in between – had even reached up to heaven. But the angels kept those stories at bay as much as possible for they did not want to be infected by human desires, so much so that they again withheld their answer. And God withdrew Himself definitively, without answering the question of why He had chosen to entrust the Law of Life to earth.

Here ends our retelling of the story.

The question is still left unanswered, however, like a pebble in the shoe. There must be an answer somehow to the angels' question?! Perhaps the answer already lies hidden in the questions of the Lord. Hence teachers have begun to study the tricky questions. After long hours of study and serious dedication, something turns up still. And indeed, not only the starting question in the story but even the Lord's questions allow for clarification: the Infinite One cannot but give the Law to humans, for the Law is not meant for heaven but for the 'earthly human person'. Thanks to one's body – one's 'own body' – the human person is capable of working, of engaging in trade, of begetting children. The human person is a being that can suffer. Precisely because one has a body, or stronger still, because one is a body. But by means of one's sensibility the human person is also touchable by and sensitive to the suffering of the other. Thanks to their 'vulnerable body' humans are bonded with each other, are attuned towards each other, are responsible for each other, and are meant to care for each other.

This means immediately that the traditional hierarchy between angels (who as spiritual beings stand closer to God and are thus loftier) and humans (who as earthly beings stand lower on the ladder of being) is reversed radically. Thanks to their so-called "low-life" nature and their bodily condition, humans stand above the angels. This is truly a paradoxical situation: the lower opens up the perspective towards the higher, the humble to the sublime! Levinas' ironic conclusion does not lie: "I do not see what angels could give one another or how they could help one another" (Levinas 1985:87). And because they do not have a body they cannot "suffer because of the suffering of the other", meaning they are not able to "be-for-the-other", to give the bread from their mouths and the products of their labour and trade to the other. Here, we touch upon not only the core of the ethical thought of Levinas but also of care responsibility, as it is revealed in a multi-vocal manner amongst people. Both the appeal to responsibility that ensues from the face of the other as

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well as the – interpersonal and organised – response to that appeal are only possible thanks to human bodiliness, and therein lies at the same time the entire spirituality of care ethics, understood as a particular form of the ethics of care, namely focusing on the care relationship in its asymmetric reciprocity. Thanks to the 'sensibility' of our body we are vulnerable by and for the other so that we as inspired or animated – literally 'ensouled' – beings are 'created' or 'conditioned' to take upon ourselves the being and the fate of the other. As Levinas says: "The tie with the other is knotted only as responsibility, this moreover, whether accepted or refused, whether knowing or not knowing how to assume it, whether able or unable to do something concrete for the other. To say: here I am (*me voici*). To do something for the other. To give. To be human spirit, that's it. The incarnation of human subjectivity guarantees its spirituality." (Levinas 1985:97).

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Being a very old science and being one of the most actual sciences (mentioned every day in the daily press), ethics is prone to being superficialised. By using a paradoxical approach ("vices for caregivers"), the authors challenge and stimulate their readers to rethink their basic ethical stance. The product is an entertaining piece of work. It takes into consideration that caretakers are not professional moral philosophers, and because of their tight schedule, need a lucid exposition.

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The authors have developed the ethical imagination inviting a sense of "otherness" towards the vulnerable self, rebounding care for the other as a way to understand our everyday neurotic (normal) tendency of small vices as the propensity and possibility for responsibility towards the other. The authors, inviting the reader into troublesome feelings such as laziness and anger, bring a Levinasian horizon into focus, so that even in the midst of laziness, there remains the small goodness to set the self free to care for the other, meeting the demands, challenges, hesitation, shuddering, tension and shocks of such alterity, of living "otherwise".

Prof. Glenn Morrison

Associate Professor in Systematic Theology

School of Philosophy and Theology, The University of Notre Dame Australia

This book offers a fresh approach to the care of caregivers. It digs into the fabric of being a caregiver and focuses on the vulnerability of the caregiver, and vices for the virtuous caring of the caregiver ... The questions at the end of each chapter can be utilised for group discussions amongst caregivers. This book makes a contribution to social sciences, in the healthcare environment for caregivers, as well as in the academic environment.

Prof. Gert J. van Zyl Dean, Faculty of Health SciencesUniversity of the Free State, South Africa

Linus Vanlaere, **Roger Burggraeve** and **Laetus O.K. Lategan** specialise in care ethics for vulnerable groups.



