

# Ethics of Care



# Ethics of Care:

*Values, Virtues and Dialogue*

By

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# INTRODUCTION

This book is about ethics of care. It focuses on mental health care, support for people with disabilities, and care for the elderly, but the ideas are also applicable in youth care, family support, home care and general health care. We pay particular attention to the care of people who are very vulnerable and have a high dependency on care, for example due to mental health problems or intellectual disabilities. Not only are they vulnerable in society and in the care context, but they also receive less attention in ethics. The most dominant ethical models are less applicable to them because autonomy and personal decision-making are paramount. In this work, we take full account of this vulnerability and care dependency.

## **Relational view**

A fundamental insight forms the basis of this book: the consistent and radical consideration of a relational view of ethics. Thinking in terms of relationships is, of course, self-evident in care. Usually, however, one starts from individuals, who relate to one another on the basis of their individuality. In a relational approach we put the relationship first: the relationship is the connection between people. They live in the field of tension between their individuality and their connection with others and their surroundings. At first sight it may seem that this is the same thing twice. But on closer inspection, and especially when we think more deeply, there is a big difference.

Right from the beginning of the book we start with the care relationship, because the concept of the care relationship determines our ethical option. We take a relational view of care, which refocuses ethics into relational ethics. This is in line with the broad movement of care ethics. We base this relational ethics on personalism. We want to interpret personalism more consistently as ‘relational personalism’. This option gives direction to all other ideas and insights in this book.

## Overview

The book consists of two parts. The first is about ethical deliberation. This deliberation can be a personal reflection process. In care, however, this deliberation is best conducted in dialogue with those involved in the care situation. In the first part, we develop a method for ethical deliberation. The first chapter deals with the care relationship as a starting point for ethics: we describe the characteristics of the care relationship, outline the different concepts on it and propose relational personalism. In the second chapter, we elaborate on the theoretical foundations of the ethical method: intuition and reflection, ethical analysis, fundamental values, proportionality of values, responsibility in dialogue, and ethical virtues. In the third chapter, we propose the practical operation of the ethical deliberation method. It is a systematic and critical method for ethical deliberation and consists of an integral model and a value test. For practical material to work with the model for ethical deliberation, we refer to the webpage: <https://theo.kuleuven.be/values-in-dialogue>

This ethical method distinguishes itself from other methods of ethical deliberation. The latter focus mainly on the procedural and communicative process of deliberation and also look at values and norms. The ‘values, virtues and dialogue’ method is not only based on the process of consultation and dialogue, but also focuses strongly on the substantive and normative elements of ethics, such as ethical analysis, values, proportionality, responsibility, dialogue, and virtues. The values test, in particular, provides a basis for the ethical evaluation of choices in care. The method has a strong focus on ‘values, virtues, and dialogue’: the values enter into dialogue with one another and are achieved in dialogue between people, while the quality of this dialogue and achievement of values is also determined by the ethical virtues of those involved.

The second part of the book deals with the ethical view of good care. To this end, we elaborate a number of relevant ethical issues for which we continually base ourselves on the method for ethical deliberation. The ethical topics are in the foreground here, rather than the method itself. In addition to the fundamental ethical view on these themes, we also provide practical guidelines. Moreover, the method for ethical deliberation can be used again and again when dealing with this view and guidelines in practice. The elaboration of the topics is more general and the ethical method bridges the gap to particular situations.

Collaboration in care runs like a thread through the seven themes. The fourth chapter concerns collaboration among care providers in a team or network. We work out the relationship between joint and individual

responsibility and address possible shortcomings of care providers. In the next chapter, we discuss cooperation with the care user and the next of kin. We discuss informed, prior, and substitute consent and make a case for care planning. The key concept in all this is discussed in the sixth chapter: the decision-making capacity. We work out a vision and concretise it in ten criteria and a working method for evaluating decision-making capacity. On the basis of capacity and responsibility, the seventh chapter develops a view of assertive care or gradual care. We make this practical on the basis of ten gradations or forms of care. We build on this in the eighth chapter on restriction of freedom and coercion. In this chapter, we distinguish between contextual, relational, structural, and situational restriction of freedom and formulate three criteria for the justification of coercion. The ninth chapter deals with the issue of information and confidentiality which plays a role in all the previous elements of care. We examine how we can deal with the duty of confidentiality and elaborate six conditions for shared confidentiality in a team or network. In the final chapter, we discuss euthanasia in the case of unbearable mental suffering, a legal possibility that exists in Belgium, and in some other countries. We clarify the ethical problem, develop a dual-pathway for accompaniment and formulate specific care requirements.

## **Key options**

As we have already indicated, we develop the ethical method and the ethical issues on the basis of relational personalist ethics. This choice has a deeper meaning for us: it turns this ethics into a Christian-inspired ethics. On the one hand, with this book we want to appeal to all care providers, regardless of their philosophical or religious convictions. We do not refer to Christian views in this book and we do not use any specific Christian language. On the other hand, we confess ourselves as Christian, and more specifically as Catholic ethicists, and we think from a Christian perspective. Relational personalism is a non-religious expression of this Christian view. Christians do not have a monopoly on this. Anyone can think relationally, but Christians have no choice but to think that way. After all, relational thinking is deeply rooted in the core of the Christian faith. Christianity is unique because it sees God as a relationship of ‘three divine persons in one’. God’s ‘inner’ relationship is expressed in the ‘outer’ relationship to creation. God connects all creatures and makes us brothers and sisters of one another. Without speaking further about God in this book, relational personalist ethics are permeated by Christian thought. The foundations of ethical methodology also find their origin in the Christian ethical tradition: the elements of ethical analysis, the fundamental values, the proportionality

of values and the ethical virtues are based on fundamental insights from Christian ethics.

In this book we also take into account the increase in legal thinking. We are witnessing a juridification of society, and this also extends to the care context. We feel a great concern on the part of care providers to act in accordance with legal requirements. We cannot refer to the various laws of different countries without becoming a book on jurisprudence, and that is not our purpose. We believe, however, that ethics has three different ways of relating to the law: a constructive input in the creation of law, a critical view of the applicable law and a complementary approach in relation to what is not regulated or not clearly regulated by law. The constructive role is not discussed in this book. The critical view runs through the entire book. In fact, legislation rarely thinks relationally, but rather sees people as individuals who may come into conflict with or have to defend themselves against one another. That is why we integrate this individualistic approach of legislation into the relational view of ethics. The final, complementary approach of ethics is also dealt with in this book. In many places we offer an ethical view and guidelines that can fill the gaps in legal regulations.

Occasionally we refer to a case or an example. This has the advantage of bringing theory closer to practice. However, this approach also has disadvantages. Discussing a case in depth risks becoming a model for readers to tackle similar cases in the same way. However, each case is different and can therefore never be approached in the same way. Another disadvantage is that a case establishes a link with one field of care or one target group. It is precisely our intention to develop an ethical view that is so fundamental and all-embracing that it transcends the artificial boundaries between sectors and users of care.

## **Process of reflection**

The book may have a somewhat positional character. It is indeed a coherent synthesis that is systematically built up from a fundamental vision into practical guidelines. But underneath this synthesis lies a whole development. The chapters are the result of rewriting courses, advice or earlier publications. And these are themselves the result of a whole process of literature study and of dialogue with care providers and students. It is impossible to allow the reader to become part of the whole process behind this synthesis. In the literature list we refer to our sources. We realise, however, that this gives only a small picture of the whole process that has gone into this work. In the list of literature, readers will find the works that have inspired us as well as suggestions for further reflection. But there are

also many unwritten sources in the practice of ethical consultation, discussion, and advice that have profoundly influenced us.

Nevertheless we will give some insights into how the ideas have been developed. In the second part of the book, we develop an ethical view on care and discuss seven current topics in care. This practical ethics is based on the ethical advice, written in Dutch and given by the Ethics Committee for Mental Health Care and the Ethics Committee for Disability Care at the Organisation Brothers of Charity in Flanders, the Dutch-speaking part of Belgium. These ethical opinions can be downloaded on the webpage: <https://broedersvanliefde.be/ethiek>. Although these Ethics Committees have only local authority, they have expert knowledge in the particular field of mental health care or disability care and their advice might have a broader interest. The Ethics Committees are composed of about twenty experienced care providers and representatives of users and family associations. The members opt for a methodological approach that combines ethical discussion with the study of literature: the moral intuitions and practices of the participants are mutually confronted with insights provided by a number of scientific publications. In the first instance, the moral intuitions and practices of the members are shared within the committee and inventoried. In the second step, the intuitions and practices are clarified and critically evaluated by comparing and contrasting them with one another and with the insights found in the literature. Consequently, we put together a draft opinion. In a fourth step, the committee discusses the draft opinion and introduces a number of amendments. In the fifth step, the new draft opinion is presented to care providers working in the field and the user and family associations, and their remarks and observations are integrated into the text. Finally, the draft opinion is discussed and amended until the committee members are able to reach consensus. The entire process takes place within a forum that is open and free, thus allowing each participant to speak their mind without any form of pressure based on authority or function. The description of this methodology gives a limited picture of the process which allowed us to formulate the ideas of this book.

## **Terminology**

The terminology chosen requires some explanation. We talk about care user, next of kin, and care providers. It is a choice that is not ideal, but hopefully good enough. Care is a central concept. The term care provider, a comprehensive term covering all care professions follows logically from this. We prefer care user to other terms such as patient, client, or resident because these are too specific for some sectors of care. We opt for next of

kin because it is a broader term than family and does better justice to the reality of a social network. As far as possible, care providers is used in the plural to point out the collaboration in a team or in a professional network. The care user is in the singular as much as possible to emphasise the personal approach in the care relationship. We also try to use inclusive language so that neither women nor men feel excluded.

Further on in the book we use the ‘we’ form. There are two reasons for this. First of all, we want to take the reader into our train of thought and also to make it clear that the ideas formulated do not come from one person, but have grown in dialogue with others. Secondly, we want to involve the care providers at whom this book is aimed. The ‘we’ form therefore stands for the care providers, and by extension and depending on the context, also for the other parties involved in the collaboration. We hope we have not excluded others who are not care providers and who read the book. We invite them to align themselves with the position of the care providers.

## Acknowledgements

Finally, I would like to thank a number of people. First and foremost, I want to thank the many care providers and students I have met in their fields of work, in ethics committees, in education and training. Through the many encounters I have had with them, I have become acquainted with the practice of care. Without them, this book would be unthinkable. Their questions, comments, and suggestions have given me much food for thought. This book has emerged from the setting of my insights and experiences as an ethicist alongside their insights and experiences as care providers. “Du choc des idées jaillit la lumière”: light emerges from the clash of ideas. I am writing about ethical best practices but they are living it out on a daily basis.

I also thank my colleagues at my two workplaces: the Faculty of Theology and Religious Studies of KU Leuven (Catholic University of Leuven) and the Organisation Brothers of Charity in Belgium. In these two places, I am given many opportunities to carry out fundamental study and research and to disseminate the results in education and ethical support in the practice of care.

My thanks also go to Cambridge Scholars Publishing. They were happy to publish this book which is the translation and updating of the third and revised edition of the original Dutch-language book (Liégeois, 2019). Thanks to them for the excellent cooperation. Many thanks also to Jane McBride, member of the Episcopal church, and interpreter at the European Commission and Parliament in Brussels, for her very careful proof-reading

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# **PART 1**

## **ETHICAL DELIBERATION IN CARE**

# CHAPTER 1

## ETHICS AND CARE RELATIONSHIP

In the first chapter we begin by elaborating a method for ethical deliberation and then, in the second part, we discuss ethical themes based on this method. The first chapter outlines the starting point for ethics of care: the care relationship. In the second chapter we discuss the foundations of the ethical method, and in the third chapter we explain its different elements.

The basic principle of ethics is that the partners in care are in a relationship with one another. We first describe the ethical characteristics of the care relationship that are derived from the symmetry and asymmetry of the relationship. Next we sketch the different concepts of the care relationship and its historical development. We opt for a relational concept in which the connectedness of people is central. Finally, we deepen this relational concept by basing it on a relational personalist ethics.

### **Ethical characteristics of the care relationship**

#### **Ethical nature of the care relationship**

The care relationship between the user and the providers of care is the starting point of a practical ethics of care (Tronto, 1993; Van Heijst, 2011). If we take an ethical approach to a situation of care, we first of all see that it takes place within a relationship of care and that this relationship of care is part of a network of relationships. Within relationships of mutuality, the various partners in care relate to one another: care user, next of kin, care providers and other parties involved. Ethics happens within that network of relationships. The very first thing we face when making ethical choices and taking action is the realisation that we are in relationship with one another.

Imagine the following case. Peter is an elderly man. Since he has been suffering from dementia, he has been admitted to a care facility. His wife and son visit regularly. During visiting hours, the son sees that his father is physically restrained in his seat. He is very upset and addresses the care provider, who tells him that it is necessary because his father constantly wants to walk around: "It would really be irresponsible to let him do what he wants to do. He doesn't really know what he's doing and he'd definitely

fall and break something. He would also bother other residents and go into their rooms. We can't sit with him all day!"

Before we ask ourselves whether this physical restraint of Peter can be justified, we are confronted with the fact that the question is situated within a network of relationships: Peter, his wife and son, the care providers and the other residents. Asking an ethical question and looking for ethical answers takes place within a network of relationships. It is important that these relationships in themselves have an ethical character because the parties involved are in a certain relationship to each other. Prior to choosing, deciding and acting ethically, we are already ethically involved in the way we relate to each other. The care relationship itself has an ethical nature because it has a certain structure with certain characteristics.

On the one hand, this structure is symmetrical because the partners in care are all human. As human beings, we have equal dignity and strive for reciprocity in the relationship. On the other hand, the structure of the relationship is asymmetric because the partners are in an unequal position in the care relationship. This inequality concerns our vulnerability, dependence and power. The tension between symmetry and asymmetry calls on us to take responsibility. We will work through these ethical characteristics of the care relationship in sequence. How these characteristics relate to one another is shown schematically in the following figure.

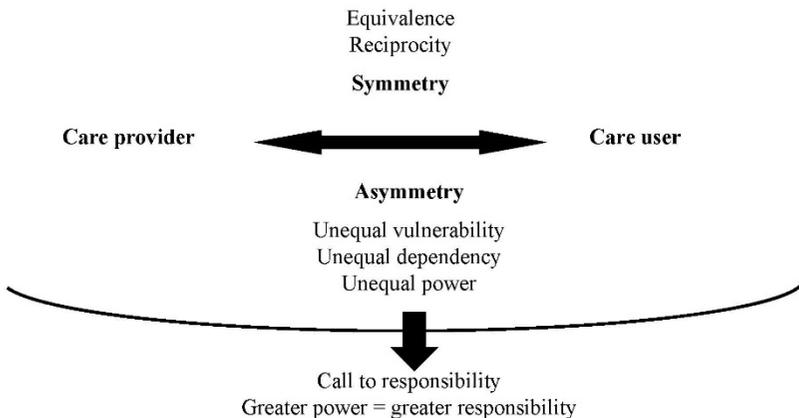


Figure 1: Ethical characteristics of the care relationship

### **Symmetry: equivalence and reciprocity**

We can view the care relationship as a symmetrical relationship because the partners in care relate to one another as equals. First and foremost we are all human. A primary, fundamental ethical characteristic of the care relationship is therefore the equivalence of the partners. We are fundamentally equal because we are human beings and bearers of the same human dignity. A foundation for this equality can be found in the related monotheistic religions, such as Judaism, Christianity and Islam. These religions profess that people are created in the image and likeness of God (Gn. 1,26). All people, despite their many differences, are equally the image and likeness of God. The equal dignity of human beings finds its roots in our common creation by God. A similar justification can be found in a secular way in the Universal Declaration of Human Rights. The preamble states that the “basis” of human rights lies in the “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family” (UN, 1948, preamble). The inherent dignity of the human being means that this dignity is part of the essence of our humanity, that it is derived from nothing else, and is therefore a necessary and inseparable part of being human.

Equivalence lies at the basis of reciprocity, a second ethical characteristic of the care relationship. Reciprocity refers to the relationship between the partners in the relationship. There is reciprocity when we are mutually involved. This is expressed in words but also in actions. We communicate with one another. Both sides listen and talk to one another. We also take actions in relation to one another. On both sides there is giving and receiving. This giving and receiving are linked together and call one another forth. Care providers offer care and at the same time receive satisfaction and recognition for what they do. The person cared for receives the necessary care and at the same time expresses recognition and satisfaction. Depending on whether or not this is enough, the relationship can be less reciprocal or non-reciprocal and more difficult to maintain. Reciprocity means that there is symmetry in the relationship, a balance between listening and speaking, between receiving and giving. This should not be understood as quantitative measurement, but rather as a qualitative experience of mutual commitment to one another.

### **Asymmetry: vulnerability, dependency and power**

We can also see the care relationship as an asymmetric relationship because the partners are in an unequal position. Although we are fundamentally

equal and strive for reciprocity in the relationship, it is also asymmetrical and marked by inequality. In the practice of care, care users and care providers find themselves in an unequal situation. The care user has a problem that he or she can no longer carry alone without professional care, while the care providers have professional knowledge and skills to deal with this problem. In addition, the care user discloses a great deal of confidential information, while the care providers do not. This creates an uneven or asymmetric relationship between the care user and the care providers. This relationship is inevitably a relationship of unequal vulnerability, dependency and power.

People are vulnerable, a third ethical characteristic of the care relationship. It means that we are frail and fragile, that we can be easily damaged in our health and integrity, but also in our relationships and connectedness. It does not take much to damage these important areas of life. In this first sense, being vulnerable has a negative connotation: we can be harmed. But vulnerability has also another meaning. To be vulnerable means to be receptive and sensitive, to open ourselves up and make contact with our own world of experience and that of others. Hence, vulnerability has a positive connotation: we can allow ourselves to be touched. Both meanings are also connected. It can be a strength to be vulnerable and thus to recognise and accept our vulnerability. However, the vulnerability in the care relationship is unequally distributed. Even though care users and providers are vulnerable as human beings, the vulnerability in the first sense of the word is usually greater for the care user because he or she is more dependent on care.

Vulnerability is linked to dependency, a fourth ethical characteristic of the care relationship. We are vulnerable in our relationships because we depend on the reciprocity shown by the other in the relationship or the equivalence acknowledged by the other. In our time and culture, dependence usually has a negative connotation. It means that we are not independent, that we are subordinate to others, and that others make the decisions. This negative connotation is related to an ideal image of striving for independence. That image clashes with boundaries, because, if we highlight independence, we find ourselves completely alone and there is no longer any relationship. We wish to present a different concept of personhood in which the human person is first and foremost connected, or, in other words, becomes a human being through relationships. Living in relation means that we put our independence into perspective, experience it in connection to others, and accept and fully appreciate our dependence on others. Moreover, it is not just a one-sided dependence on the other, but interdependence with one another. Viewed in this way, interdependence is an essential feature of

relationships and of being human.

The asymmetry of vulnerability and dependency in the care relationship leads to an unequal distribution of power. This is a fifth ethical characteristic of the care relationship. Power is the ability to do something or to exert influence. In this sense, power is positive and essential, so that people can interact with each other and influence each other in their relationships. Without mutual influence, there is no life and movement in relationships. But power also has a negative connotation when it refers to the ability to control and reign over the other. Both approaches to power are in line with each other. There is a gradual scale for power: from acting and influencing, to controlling. In the care relationship we do not like to control power because we think that this does injustice to the fundamental equality of people and to the necessary reciprocity in the relationship. Yet power as control is never far away when we understand power as influence.

Because the care providers and the care user are in unequal positions in the care relationship, power is always present. Usually the care providers have more power because they have professional expertise and authority to make decisions from their position. Of course, the care user can also exercise power over the care providers and the care providers can feel powerless. Usually the care user is confronted more with vulnerability, dependency and powerlessness because he or she is in a situation in which care by others is necessary. Nevertheless, care providers are also vulnerable, dependent and sometimes powerless. In any case, there is an uneven distribution of power, vulnerability and dependency. Inequality is an inescapable fact in the asymmetric structure of the care relationship.

### **Call to responsibility**

There is a field of tension between the symmetrical structure in which we are equally and reciprocally in relation on the one hand, and the asymmetrical structure of an unequal position due to our vulnerability, dependence and power on the other hand. There is a tension between the principled symmetry that we strive for as an ideal and the factual asymmetry that is given in reality. This field of tension between ideal and reality in the care relationship creates the ethical task of turning actual inequality into fundamental equality as far as possible, even though the inequality in the relationship is structural and insurmountable. The tension leads to the call or the duty to assume our responsibility and to deal with the inequality in a responsible manner. The actual inequality of power, vulnerability and dependency becomes ethical depending on the way in which we assume our responsibility to deal with it in the care relationship.

Care providers and care users have a certain amount of freedom when it comes to assuming their responsibilities. If we use the vulnerability or dependency of the other or our own power to our advantage or to the disadvantage of the others, then the relationship becomes unethical. As a result, the fundamental equality of people and the necessary reciprocity in the care relationship are also compromised. Because as care providers we are usually less vulnerable and dependent than the care user and because we usually have more power than the care user, we have the greatest responsibility for interacting ethically with one another in the care relationship. Taking on board this responsibility is therefore a determining factor in how we deal with the different characteristics of the care relationship.

In dealing ethically with equality and reciprocity, with vulnerability and dependence, with power and responsibility, the concept of the care relationship plays an important role. Depending on their concept of the care relationship, care user and care providers will pursue different goals, relate to each other differently and interact with each other differently.

## **Concepts of the care relationship**

### **Development of concepts and paradigms**

There are many concepts of the care relationship (Charles, Gafni and Whelan, 1999; Emanuel and Emanuel, 1992; Liégeois and Van Audenhove, 2005). A concept is an approach, a view or an idea of reality and of how that reality might best develop. In order to create theoretical clarity, we distinguish three concepts, depending on whether we are looking from the perspective of the care providers, the care user, or the relationship between care providers and care user. In these concepts, a different relationship is established between the ethical characteristics of the care relationship. We will set all three perspectives within the process of historical development in Western culture. Thus can we recognise the movement from a traditional to a modern, and further to a relational concept.

Within each concept we can distinguish even more paradigms. A paradigm is a model or a general theoretical framework according to which we interpret reality in a certain culture and in a certain period of time. If we look at the care relationship from the point of view of the care user within the modern concept, we can discern two paradigms: an emancipatory paradigm in which we see the care user as an autonomous individual, and a societal paradigm in which we see the care user as a citizen in society.

These concepts and paradigms are theoretical models and thus ideal-typical approaches. In the practice of care we can of course combine them. In such combinations, a single concept or paradigm will dominate, but there are also elements from other concepts present. However theoretical these concepts and paradigms may be, they help us to gain a better understanding of the care relationship and its development. Below we outline the historical development of these concepts and paradigms. The mutual relationship is shown schematically in the following figure.

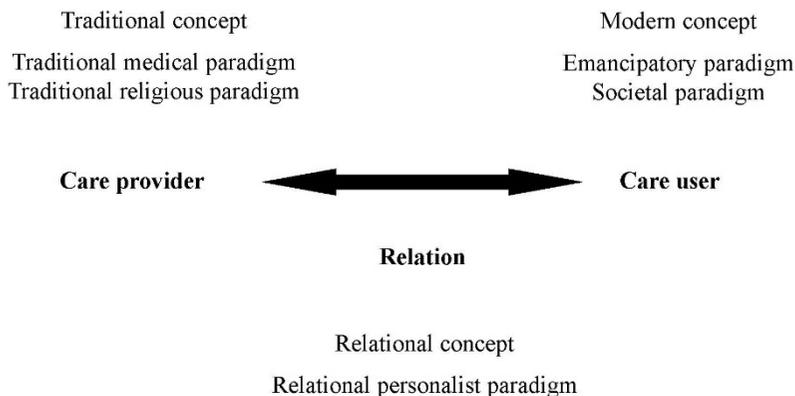


Figure 2: Concepts of the care relationship

### **Traditional concept: traditional medical and religious paradigm**

From the asymmetric relationship between care providers and care user it is clear that the traditional concept of the care relationship is determined from the perspective of the care providers. It is they who first reflect on what good care is. For the care providers, their specific competence and their human commitment are the basis of care. They state that they know what is good for the care user, based on their professionalism and commitment. Support and professional responsibility are paramount. They provide the ethical justification for the actions of the care providers.

The traditional concept is based on the medical paradigm of care. In this paradigm, the ethical reflection on care was developed from the Hippocratic tradition in medicine from the 4th century BC. In the Hippocratic Oath the focus is on doing good and not harm. The physician makes every effort to heal the care user and to keep them alive. In addition, the physician should

not cause any damage to the health or integrity of the care user. Beneficence and non-maleficence are the basic principles of the centuries-long tradition of medical deontology and of the professional ethics of the other care professions.

This medical paradigm is supported by the religious paradigm of the monotheistic religions in the Western world, especially Christianity. Believers are called to charity. This means that people can only love God by loving their neighbour and thus working selflessly for their fellow human beings, especially for the 'poor' and 'needy'. When it comes to deeds, the charity of believers and the beneficence of physicians go hand in hand, even if they have different motives. Moreover, believers have a great respect for life from the point of view of belief in creation. Life not only has a human character, but also a holy character: it was created by God. Consequently, the respect of believers for the sanctity of life is in keeping with the principle of non-maleficence by physicians.

Moreover, the beneficence and the non-maleficence of medical deontology are fully in line with the two basic rules of natural law, which plays an important role in Christian ethics. Doing good in natural law is consistent with beneficence in medical deontology, and avoiding evil in natural law is consistent with non-maleficence. This implicit alliance between Christian morality and Hippocratic deontology has underpinned care ethics in a centuries-long tradition. That is why we explicitly call this the traditional paradigm in medicine and religion, because there are also more contemporary medical and religious concepts possible. We must not underestimate the importance of this traditional paradigm, which has lasted for more than two thousand years.

Too much emphasis on the support and responsibility of care providers can, however, reinforce the asymmetrical nature of the care relationship, increase the power ratio and lead to paternalism or patronising attitudes. Then the care user in particular will feel vulnerable, dependent and powerless. Although we can interpret paternalism positively, it usually has a negative connotation. A positive interpretation of paternalism is that the care providers, for the sake of the care user, act based on their view of what constitutes good support. However, paternalism takes on a negative meaning if the care providers do this without giving the care user sufficient say, even though he or she has the ability to help determine the choices in care. Such paternalistic action strengthens the asymmetry and the imbalance of power in the care relationship.

However, an approach from the care providers can also be different. The care providers can act on the basis of their professional responsibility, and give the care user a say at the same time. The condition is that the care user

has sufficient decision-making capacity. Sometimes care providers have no choice but to go against the wishes of the care user on the basis of their professional responsibility. The danger of paternalism is never far away in the traditional concept of the care relationship. Care providers should not be over hasty in deciding that the care user is not competent to make certain decisions.

### **Modern concept: emancipatory paradigm**

In response to the danger of paternalism, the modern concept emphasises the perspective of care users. In this concept, it is no longer possible for care providers alone to decide what is good in the care relationship. The care user has the right to make their own choices in care. The autonomy and personal responsibility of the care user are paramount here.

The practice of this autonomy is not simple, because the care relationship is asymmetrical. After all, the care user has a problem that he or she can no longer solve alone, while the care providers have the knowledge and skills to deal with that problem. It was in order to give shape to autonomy in this asymmetrical relationship that the concept of informed consent was introduced. This means that care providers may only provide care if they inform the care user in advance, and if he or she agrees to this. Informed consent is a practical way to ensure respect for the autonomy of the care user. It also provides the ethical justification for the actions of the care providers.

The foundations of this concept can be found in the emancipatory paradigm in care. Its historical roots lie in the Enlightenment from the 17th century onwards when philosophers argued that people should dare to think and free themselves from the patronage of church and authority. For the care sector, this emancipatory idea broke through as a paradigm from the 1960s onwards, amidst a worldwide movement of emancipation of the colonies from their colonising countries, a movement of blacks against whites, of women against men. The emancipatory paradigm is the leading paradigm both in the organisation of care, and in legislation. Informed consent is the basis of patients' rights. By formulating rights, the legislator intends to guarantee the quality of the care relationship and the support provided. The starting point for making choices in care is therefore the care user's right to free, prior, and informed consent.

Not all care users are sufficiently competent to make certain decisions about care. This is often the case with care users who are highly dependent on care. After all, a necessary condition for the exercise of autonomy is decision-making capacity. Care users often need guidance in order to be

able to take informed and responsible decisions. Supporting or promoting the decision-making capacity of care users therefore requires a guidance process. Some care users have no insight into their situation or problems, and therefore refuse care. As a result, care providers sometimes have no choice but to go against the wishes of the care user. Another problem with informed consent is that the care providers should not be reduced to mere implementers of the wishes of the care users. They too have their views on what constitutes good care. If informed consent is interpreted too formally, care providers are obliged to implement the wishes of the care user, even though they are convinced, based on their professional competence and personal engagement, that these wishes do not serve the wellbeing and health of the care user.

### **Modern concept: societal paradigm**

From the 1980s onwards, the societal paradigm began to build on the emancipatory paradigm. In this concept, the role of society is paramount. After all, it is up to the next of kin and society as a whole to decide how the care user participates in societal life. Participation will now take priority, as will the social responsibility of the next of kin and the societal responsibility of the community.

A first tendency in this new paradigm is the socialisation of care. Nowadays, the care user is no longer seen as a purely autonomous individual, but also as a citizen in society. In order for the care user to become a fully-fledged citizen, it is necessary for care to be deinstitutionalised and offered within society. The care users have the right to participate in societal life and it is the community's task to include care users even with their limitations. If care users can no longer be cured, care must focus on restoring their capacities in order to ensure the highest possible quality of life in a societal environment.

The economisation of care is a second trend within the societal paradigm. This means that economic motives and interests dominate how care is organised. Funding for care services is scarce and there are limits to solidarity with those in need of care. This is why policymakers impose cuts and include a discussion of economic mechanisms, such as the commercialisation and privatisation of care.

A third trend is regulation, the increasing impact of rules, directives and procedures in care. The funds invested must be well spent and therefore justified. As a result, different systems are introduced to measure the quality of care and organisations providing care are required to obtain accreditation. 'Evidence-based practice' becomes the standard for care. This means that

scientific research proves that a certain intervention is effective and establishes guidelines or procedures for practice related to that intervention. Diagnostics is also increasingly linked to the effectiveness and financing of care. Another form of regulation is the legalisation of care. The law increasingly regulates care and conflicts are taken to court with increasing frequency.

These three trends have serious consequences for care. The socialisation of care expects care users to fit in with the usual pattern of living, working, and consuming. However, society is reluctant to include people with problems in societal life and the next of kin often do not feel sufficiently supported to provide care themselves. In economisation, the cost of care is increasingly shifted on to the care user and the next of kin. Nevertheless, it remains the policymakers' task to distribute resources in an equitable and sustainable manner so that care remains affordable for the care user, the next of kin and the care organisations. As a result of increasing regulation, there are more and more rules that determine the actions of care providers. These offer the care providers safety, but limit their professional freedom to deviate from certain guidelines and procedures in the interests of the individual care user.

### **Relational concept: relational paradigm**

Both concepts, traditional and modern, contain positive and negative aspects. A number of elements of a more practical nature have already been formulated in the discussion of the paradigms. However, there is also a more fundamental criticism. From a theoretical perspective, we can interpret the previous concepts as individualistic. They emphasise the individual as a self-contained being, distinct and independent from others. If there are differences of opinion, either the care providers make decisions on the basis of their professional expertise or the care user decides by means of informed consent. In both cases, one partner makes choices without decisively involving the other partners.

However, an alternative and integrative concept is possible, which emphasises the concept of relationship: care providers and care users are not only individuals in their own right, but also people in relation to others with mutual connectedness, commitment and dependence. A relational ethics actually involves three elements: one person, another person, and the relationship between them. The relation forms the connecting or integrating element. This relational concept has very important consequences. In care, support and autonomy are no longer the main values, but rather trust in the relationship between care providers and the care user. It is not just a matter

of the professional responsibility of the care providers or the care user's personal responsibility, but above all it is about the shared responsibility of all those involved: care user, next of kin, care providers, and other parties.

Based on this focus on relationship and connectedness, the relational concept also connects and integrates the traditional and the modern concepts. It tries to highlight the strengths of the concepts as applied to the care providers and the care users, and to avoid the weaknesses by emphasising the relationship between the two. This relational concept is further based on personalism.

## **Relational personalism**

### **Personalist concept**

We base the relational approach to the care relationship on a personalist concept of the human being (Selling, 1988; Smith, 2010). In personalism, we focus on the human person and approach the person integrally, in his or her entirety, looking at all dimensions of being human. This distinguishes personalism from individualism. With the word 'individual' we emphasise our independence, standing on our own feet and being able to distinguish ourselves from other people. Starting with the individual we then look at relationships and the surroundings. With the term 'person' we express our openness and commitment to people and the world other than ourselves. In personalism, we are not only an individual, but also a person. The relationship of the person to their fellow human beings and to their surroundings is central.

We wish to align ourselves with the Leuven personalist tradition in ethics, founded by Louis Janssens. More than forty years ago, he brought renewal to Christian ethics by presenting personalism as an alternative to natural law thinking. He found the philosophical basis for this in phenomenology and personalism (De Tavernier, 2009). He formulated a concept of the human person, considered integrally and adequately, on the basis of eight dimensions which are constitutive or essential for being human: the human person is a subject, in corporeality; in relation to the world, other people, social groups, and God; the person is a historical being, and at the same time each person is unique (Janssens, 1980). Janssens's concept of the human person formed the basis of personalist ethics. At the same time, it also became the criterion for evaluating whether a human act is ethically justified or not: an act is justified if it promotes the dignity of the human person, considered as a whole, on the basis of all dimensions of the human person.

Personalism is still useful and valuable in ethics. However, the philosophical and theological foundation and the justification for it are dated. Criticism is mainly directed at the observation that personalism continues to start from the subject and only comes to relational connectedness from this subject. It was therefore proposed to reverse the order of the dimensions and to start from the whole of reality in order to end up with the individual subject (Selling, 2003).

For us, this adjustment is not enough, because individuality is now inevitably undervalued. Are we primarily individuals and do we act as individuals in relation to others? Or are we first connected and do we only become individuals through the development of relationships? In either case, the individual cannot do without relationships, but there is also no relationship without individuals. We would therefore propose a revision of personalism to give a more consistent shape to the relational dimension of being human. To this end we do not focus on individuality or connectedness, but on the relational field of tension between connectedness and individuality. We experience a tension between our life as individuals and our life in relation to others around us. Focusing on this relational field of tension is seen as a revision of Janssens' personalism which we call relational personalism. At the same time, we reformulate a number of dimensions and highlight different aspects.

### **Time and space: anthropological facts**

To revise the personalist concept, we start from two fundamental and unmistakable anthropological and philosophical facts: people live in time and in space (Van Knippenberg, 2002). We cannot imagine life and the world without referring to time and space. We use these fundamental facts as a basis for shaping the dimensions of the human person into a coherent whole. We situate the person on a time line and a space line. We live in the here and now, at the intersection of time and space. The time and space lines are represented in the figure below as a cross, with the vertical line indicating time, and the horizontal line indicating space.

The time line is the historical journey we make between birth and death. This is our life history. We try to formulate the fragments into a meaningful and valuable whole. In doing so, we ask ourselves existential questions about our origin and our destination. Who am I and where do I come from? Where am I going and what is my future? We try to build a good life between our origin and our destination. This gives us three dimensions that can be distinguished on the time line, namely past, present, and future.

On the space line we place the relational tension we experience between our individuality and connectedness. This field of tension is our life world. We want to be independent individuals and we want to make our own choices. At the same time we live in connectedness with a network of relationships in a specific context. We can ask ourselves questions in our search for individuality and connectedness. Who am I and what is my identity? How can I live with others without losing myself? What are the limits of my freedom and of my responsibility? We also distinguish between a number of dimensions on the space line. To this end, we appeal to the biopsychosocial and existential model.

### **Biopsychosocial and existential model**

The biopsychosocial model was developed in health care, particularly in psychiatry (Frankel, Quill and McDaniel, 2003). It therefore provides a good basis for the dimensions of the human person in care. This model was a response to the prevailing medical model that reduced disease to a causal mechanism of biological factors. The new view considers disease as a combination of biological, psychological and social factors. The result is an approach that also takes into account people's experiences and the context in which they live. The major limitation of the model is that it does not provide a convincing foundation for the interaction between biological, psychological and social factors.

It is striking that there are only three dimensions in this model. The existential dimension was introduced into care as a result of other developments (Van Deurzen, 1997). A first development came from the existentialists who took up the challenge of existential questions in philosophy, and also from the psychiatrists and psychotherapists who gave this dimension a place within treatment. A second evolution can be found in spiritual and palliative care providers who allocated an important place within care to existential needs and spirituality. By means of these developments, the existential or spiritual dimension is added to the biopsychosocial model. We prefer the term 'existential' because it refers to the more basic needs in terms of experiencing meaning in life, whereas 'spiritual' refers rather to an elevated reality. The new four-dimensional model can be found mainly in contemporary views on quality of life and palliative care.

The social dimension, which relates only to contacts with people and groups, is extended to the entire societal, material and natural context in which we find ourselves. This brings us to four dimensions of being human: the physical, psychological, contextual and existential. We present them in

the figure below as concentric circles. The physical dimension is the core of our existence. The physical and psychological dimensions together form a psychosomatic unity, our individuality. This individuality does not stand alone, but in a broader context. In this way we come to the field of tension between our individuality and our relational connectedness with others, as well as the wider environment and context. The most far-reaching connectedness is this one with the whole of our existence, the all-encompassing dimension of life.

### **Dimensions of the human person**

On the basis of personalism, the anthropological facts of time and space and the biopsychosocial and existential model, we distinguish eight dimensions of the human person. This is also a revision of the dimensions proposed by Janssens (Liégeois, 2017a).

We place the human person on a space line with a number of dimensions in the field of tension between individuality and connectedness. People are connected through relationships. This is a reference to the social dimension of the biopsychosocial and existential model. We expand it into a cluster of contextual dimensions because people are not only involved in social relationships, but are also part of a wider network and context. We can distinguish different forms of connectedness: people live in (1) a network of social relations, (2) a societal environment, (3) a material world, and (4) a natural world. Social relations concern relations with our next of kin, including family and relatives, but also with our circle of friends and acquaintances and within our work context. The societal environment consists of our place in society, our participation in social groups, and our relationship to culture as a set of lifestyles and habits. The material world refers to the goods we need and the economic system of production and consumption in which we participate. The natural environment refers to nature, the cosmos, and the ecological system of which we are a part.

By living in this connectedness we become a fully human person, and therefore also an independent individual. Our individuality is based on a psychosomatic unity. In this way we come to two new dimensions: persons are (5) physical beings and (6) psychological beings. By physical dimension we mean our physicality. The psychological dimension refers to our feelings, thoughts, and motives. It is precisely because of the physical and psychological dimensions that we come into contact with others and with the world. Psychosomatic unity is focused on connectedness in relationships and in a certain environment.