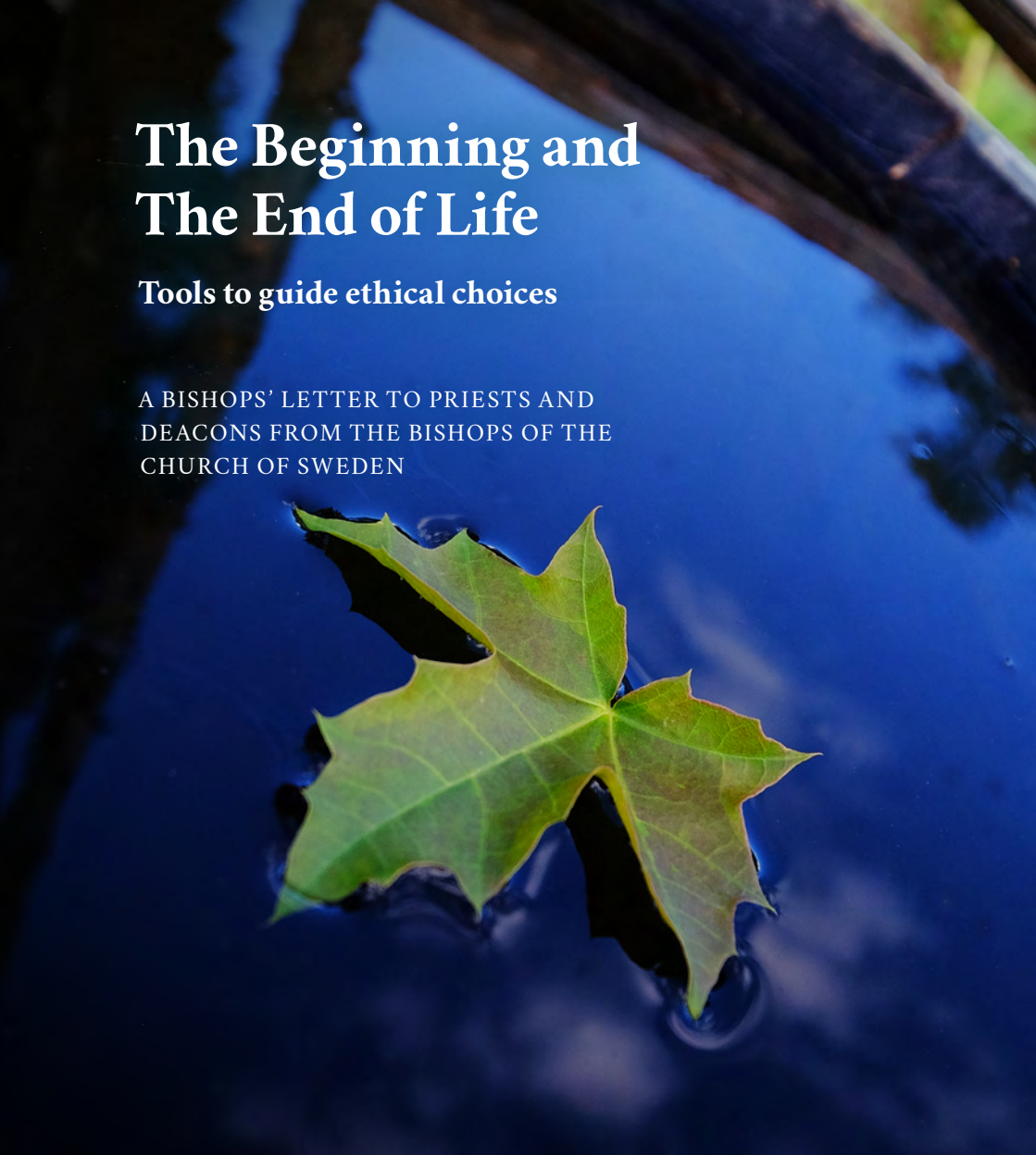
The Beginning and The End of Life

Tools to guide ethical choices

A BISHOPS' LETTER TO PRIESTS AND DEACONS FROM THE BISHOPS OF THE CHURCH OF SWEDEN



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Foreword

In this bishops' letter, we want to provide tools to guide the choice of ethical path concerning issues at the beginning and the end of life. Many different answers are offered in society to ethical questions about the beginning and the end of life in many different ways. The paths to the positions adopted also vary. Even for Christians, our starting points and conclusions may differ. In specific situations, when decisions have to be made, many people feel like they are on their own.

However, the fact that there are multiple answers does not make them unmanageable. The paths to the answers vary, but we can discuss them. Our Evangelical Lutheran tradition emphasises the responsibility of each person to make their own ethical decisions, but we can guide each other and critique each other's views. For not only do we bear responsibility, we are also equipped with abilities that help us find ways to make decisions.

We obviously wish there were quick answers to difficult questions, but when reading this letter, it is best to let go of any expectations of easy solutions. The letter is intended to be read slowly and discussed quietly with others, using the tools we present.

We want to provide common tools for gaining a more in-depth understanding of the issues – with tools that naturally can and should be developed and expanded upon. We also want to show

how the tools can help by providing examples of their application.

This bishops' letter is addressed primarily to those who are in the church's ministry, to priests and deacons. After first using the tools for personal reflection, they can then be passed on to help others as they wrestle with questions about the beginning and the end of life. This applies to individual pastoral care, teaching in the parish, supportive conversations with staff in health and social care and the emergency services, as well as to public debate.

On the basis of a Christian view of human beings and ethical principles, we can, individually and together, meet people's expectations for support and guidance from the church when the big questions need to be answered. We can do this without any ready-made answers, out of respect for each other and for the complexity of life and death.

Knowledge seeking, reflection, dialogue and prayer both challenge people and provide us all with comfort. In all of this, we can also rely on what Paul, in his famous words in Romans 8, reminds us: the promise that neither life nor death can separate us from God's love.

Uppsala, Epiphany 2024

Martin Modéus
Archbishop

Introduction

The questions asked at the beginning and the end of life have no definite answers. But sometimes they still need to be answered. Can we really cope with another child? Should I stop my cancer treatment now? We have to make a choice, but still we cannot be sure that we did the right thing. And sometimes we think we know that it will be the wrong choice, but do not have the strength to make a different one. We have to live with the consequences of our choices. It can be difficult to talk to others about this.

What is there in Christian faith and tradition that can help us be better prepared? By familiarising ourselves with the issues and expanding our knowledge of the tools available for reflection, we increase our chances of finding a way to make informed ethical decisions. This is true both in specific situations and when dealing with discussions of the issues regarding the beginning and the end of life. The bishops' letter brings together theological perspectives, ethical reflection and sensitivity to existential issues.

Christian faith is primarily a relationship with God – not a rulebook with ready-made answers to all questions. But faith does provide us with tools that enable each and every one of us to address deep existential questions. What is a life? When does it start? When does it end? With this bishops' letter, we want to con-

tribute to the discussion which ultimately is a negotiation regarding the human condition. The focus is on tools that Christian faith and ethics provide us with when important values are at stake. With this letter, we want to help strengthen our theological ability to make informed ethical choices.

We are mainly focusing on providing priests and deacons with support and inspiration for ethical reflection. We want to prepare the ground for conversations in the parishes and, for example, in the work to support staff in health and social care and the emergency services. We also want to contribute to the collective reflection on how society should approach these ethical and existential questions. Our starting point is an ethical framework based on Christian faith, but also we recognise that interpretations of what is to be included in this framework may differ between and within churches.

Regarding those issues on which the Church of Sweden has adopted an official position, it is important to convey information about this and how these positions are rooted in Christian faith and conviction. It is equally important in this letter to clarify how ethical principles can offer guidance for a dialogue in which people may come to different conclusions. The tools we present here are not only intended to be used for individual reflection or pastoral care. They also provide guidance when the voice of the Church of Sweden is sought in public discourse. They give everyone access to the theological basis for the positions we adopt.

It is necessary to take a pastoral approach characterised by

humility. Navigating between openness to different points of view and clarity in one's own reflection is not an easy task, but it is a key aspect of professionalism in the church. A robust knowledge of a Christian view of human beings and ethical principles provides metaphorically speaking a map and compass that serve to guide wanderings in this terrain.

As priests and deacons, we meet people in our parishes who are struggling with issues regarding the beginning and the end of life. We also need to process these issues ourselves. It is obviously not appropriate for priests and deacons to engage in their own reflections during work in their parish. This should take place in other contexts, such as in staff groups or at deanery meetings.

Parishes have opportunities for general discussions on the issues. The church is a valuable forum that differs from other forums, such as that of healthcare. Healthcare professionals are in particular positions of responsibility in terms of making decisions, as well as crucial prioritisations, on behalf of and with others. The church's own forum is also separate from concrete political decision-making on legislation and resource allocation.

But above all the church is the place where people from different professions and areas of responsibility in society come together as parishioners. There is also space for encounters with those wishing to challenge the Church of Sweden or, conversely, those who consider that we make valuable contributions, even if they do not share Christian faith. Our primary responsibility relates to the existential dimensions of the issues, based on a Christian view of

human beings and guiding ethical principles.

Important insights are expressed in the text of Psalm 8, which has been read and used in prayer for over a millennium. It asks the important question of what a human being really is. The answer to this question has several dimensions. Human beings are subordinate to their creator and part of an infinite universe. But they are not insignificant; they are entrusted with vast resources and are creatures who bear responsibility. And God cares for us, thinks about us and takes responsibility for us.

> When I look at your heavens,
> the work of your fingers,
> the moon and the stars that you have established;
> what are humans that you are mindful
> of them,
> mortals that you care for them?
> Yet you have made them a little lower than God
> and crowned them with glory and honor.
> *(Psalm 8:3–5)*

Our biblically based faith needs to be linked to contemporary knowledge. The beginning and the end of life are areas in which medical developments are pushing back the boundaries. This applies both to what it is possible to know, for example about genetic predisposition and the conditions for the seriously ill, and what it is possible to do in terms of influencing the conditions of birth and death.

There is much in relation to birth and death that human ingenuity has helped to improve. The ability to monitor foetal development means safer pregnancies and deliveries for many. Alleviating symptoms and understanding the human ability to mobilise resources to deal with illness, and ultimately death, means that much suffering can be avoided and alleviated.

Christian tradition assumes that human beings are 'a little lower than God' while at the same time being 'mortal', as the psalm puts it, and thus limited. Evangelical Lutheran theology emphasises that each human being is 'empowered' to take responsibility. Inherent in this is the conviction that God has endowed human beings with abilities and given them the responsibility to make decisions about their lives. This is a fundamental concept in the Evangelical Lutheran tradition. The responsibility is therefore always that of the individual, but we are part of communities that can provide support and guidance. The church is such a community. With this letter, we want to help strengthen our theological ability to make informed ethical choices. This also applies when people do not come to the same conclusions. The ethical debate must always be conducted with respect for other points of view and without judgement of people holding those views.

Outline and scope

The letter is in three main parts. The first describes a Christian view of human beings using four conceptual pairs: created and co-creator; person and community; freedom and responsi-

bility; righteous and sinners. The second describes four ethical principles that provide guidance when making ethical decisions and choices regarding courses of action. These are rooted in a Christian view of human beings and ethics: the principle of human dignity, the principle of responsibility, the principle of the best interests of the child and the principle of justice. The third and final part discusses four questions using these principles. The section on the beginning of life starts with the issue of prenatal diagnosis and then addresses the issue of abortion. The section on the end of life starts with the issue of organ donation and then addresses the issue of assisted dying. The questions in each section are linked in that they start off with questions asked of everyone in a given situation: everyone who becomes pregnant is offered prenatal diagnosis, and everyone is encouraged to enter their wishes in the donation register. The issues of abortion and assisted dying relate closely to these broadly relevant starting points, even if they do not affect everyone in the same way.

Other issues could also be addressed. Our intention is not to be comprehensive. The focus is on the tools we present, with the case studies indicating how they can be applied in concrete terms. In the transition between presenting a view of human beings and the ethical principles, general issues of ethics based on Christian faith are addressed.

It is our hope that the reader of this letter will at the same time reflect on different applications. The specific examples we provide are limited. We have only been able to touch briefly upon

the variety of different circumstances surrounding issues at the beginning and the end of life. There are links to current political debate upon which we do not see it as being the task of a bishops' letter to comment. However, readers are given the tools to engage with the issues of the day. The complexity of the interplay between ideal and reality is also only hinted at. For example, the letter does not analyse differences between legal rights and the actual resources required. The full diversity of life, with all its difficulties and complications, cannot be covered in this short document. However, the tools are intended also to be relevant to situations that are not explicitly mentioned. See this letter as a starting point – a common framework. The content can and should be developed and expanded upon in different contexts. What we provide in this letter are tools to address ethical issues of great importance for our time, based on Christian faith and tradition.

The letter contains different types of sections: examples, fact boxes and summarising sentences at the end of each presentation of the four principles. Finally, there is a list of references in which the Church of Sweden's position on specific issues is also summarised.


Alla människor är viktiga.
Alla dagar!

I A Christian view of human beings

Our theological foundation is based on a Christian view of what a human being is. Psalm 8 has a great deal to say on this subject, but the Bible also contains further descriptions of human beings and Christian theologians have reflected over the centuries on what characterises the human condition.

A characteristic of an Evangelical Lutheran view of the human being is that she cannot be described in a single word. There is always a dialectic element, a conceptual pair – "both/and". Four key perspectives in this regard, expressed as word pairs, are as follows: Human beings are both *created* and *co-creators*, both *individual persons* and *part of communities*, both *free* and *responsible*, both *righteous* and *sinners*.

> *If a woman is pregnant and is asked whether she wants to take a test to find out whether the foetus is the carrier of a serious disease, the situation encompasses all these dimensions in the following manner: The woman shares in the human ability for co-creation through medical advances, which means that she can decide for herself whether she is willing and able to have the child in a way*

that is completely different to the prospective parents of previous generations. At the same time, the choice can feel overwhelming. After all, she is only human. When making this choice, on the one hand, the woman stands alone as a person. On the other, both the woman and the foetus are part of a context: a partner who is happy or concerned about the pregnancy, a family that is supportive or questioning, a society that sets conditions for and limitations on the help it can provide. The woman has a freedom that allows her to make different choices, depending on what the test shows. At the same time, she has an inescapable responsibility to make a choice that has consequences for herself, the foetus, her partner and other people around her. Whether the woman chooses to take the test or not, she has to live with the consequences. She will also be faced with new choices. The concept of human beings as being simultaneously righteous and sinners is an acknowledgement of the duality of life. God always gives us new confidence and strength to live life as it is. There is always hope.

We will now elaborate on what these dialectic conceptual pairs mean.

Created and co-creator

Fundamental to a Christian view of human beings is that humans are created by God, in God's image. Contemporary theology has highlighted the role of humans as co-creators in God's ongoing work in creation. The concept of being created helps us to recog-

nise that we are dependent and limited, both in relation to God and to the rest of creation. The concept of being co-creators emphasises that we can make a bold contribution to the development of creation and push back the given boundaries of the past. However, both concepts in this dialectic pair are valid. As human beings, we need to manage both the limitations and the opportunities – and recognise that there are strengths in both.

The belief that we are created by God also means that God wants us to live in loving fellowship with God and all of humankind. Each person is created in God's image. There is something that binds us all together – not in spite of our differences, but with our differences being fundamental to our common ability to co-create. We also believe that God became human in Jesus. This means that nothing human is foreign to God. God shares human life with us, in all its complexity and vulnerability.

One way to talk about humans as co-creators is to talk about stewardship. In Genesis 2:15 it is expressed as working and caring: "The Lord God took the man and put him in the Garden of Eden to till it and keep it." The Gospels contain other accounts of humans as stewards (e.g. Luke 12:42, Luke 16). Stewardship is the task of taking responsibility for something that belongs to someone else, usually in the long term. Humility is therefore inherent in the concept of stewardship. Here lie both the limitations and the opportunities.

God is not finished with creation. God creates continuously, with humans involved as co-creators. This is referred to in the

Evangelical Lutheran tradition as our calling. Human beings have a calling to act in the world in a way that contributes to welfare and prevents suffering and hardship. This also includes a calling to care for and protect creation, respecting its intrinsic value and taking into account the needs of future generations.

Person and community

Talking about a human being as a person rather than an individual makes a difference. Whatever term is used tends to lead the mind in different directions. Stating that ten 'individuals' lost their lives in an accident gives one type of association. If we instead say that ten 'people' lost their lives, our thoughts move in a different direction. The 'individual' stands alone; the 'person' is surrounded by others. Choosing to talk about persons means emphasising that human beings are both independent and dependent. In other words, we are persons who are both autonomous and relational.

Thus, as stated above, the conceptual pairs are not mutually exclusive. The choice between 'person' or 'individual' in the context of 'community' presents a challenge that requires comment. It is very much a question of the language used. It is also possible to talk about individuals who are independent and also form part of communities. However, what is implied when talking about individuals rather than persons is usually a more isolated form of autonomy. On the other hand, the term 'person' may seem too close to the notion of community. The person's autonomy risks being subsumed and concealed by the community. We therefore

emphasise that we perceive the person as being both autonomous and relational.

We were reminded that no human is an island during the corona pandemic, when many testified to the negative psychosocial effects of social distancing. Describing human beings solely as independent individuals risks giving the impression that this is how we are meant to live – disconnected from other people. Central to Christian theology, however, is the notion that humans are never fully autonomous, but are also always deeply dependent on community and context, on their relationships with God and their fellow humans.

This does not mean that independence is of no importance. Both independence and community are necessary. This is important in relation to how we view society. Self-determination is central to a democracy, with every person having a say in shaping society. When it comes to making decisions about the beginning and the end of life, we make decisions as independent persons. We may be surrounded at these times by communities that support us, not only in our choices, but also on the path towards them. But communities can also become oppressive and destructive in a way that makes it necessary to protect the person's independence.

Self-reflection and rationality are often emphasised as being what characterises a 'person'. Are there humans who are not persons in this philosophical sense? Very young children, for example, seem to lack the ability to engage in the self-reflection that is considered to characterise a person. A similar inability may be

found in people with severe cognitive disabilities. Contemporary theology has drawn attention to how we are to understand the concept of being made in God's image described in the story of creation in Genesis 1. In the World Council of Churches' document *The Gift of Being*, this is interpreted not in terms of our human abilities, but as referring to our very existence. In being created by God, we have been given the gift of existence, which is a gift we pass on by simply existing. Everyone has the ability to be a person and to be part of a community.

What does it mean that humans are also in fellowship with God? Baptism gives us the keys to understanding how deeply the relationship with God and the relationship with other humans are rooted in each other. Baptism can be seen as a programme for how to live life. The opening words of the baptismal service state:

> We are baptised into fellowship with Jesus Christ,
> with all those who, through the ages,
> and all over the world, wish to follow him in life and death,
> with hope of resurrection.
> Baptism does not distinguish between people.
> No one is greater or smaller, first or last.
> All are one in Jesus Christ.

Baptism binds us together and sends us out in service of the good. Those who are baptised are incorporated in the worldwide Christian fellowship, each with the task of being a Christ to their

neighbour. As human beings, we are dependent on each other's care. We are vulnerable, and everyone needs to be carried by others sometimes. When I am fending for myself, I have a limited perspective regarding who I am and who God wants me to be. Through help from others, God gives me new opportunities to discover how the good life to which God calls us can be shaped and realised.

The help that God provides through other people – regardless of their faith and philosophy of life – is a manifestation of God's grace. All those baptised have the task of delivering to others the liberating message in the Gospel of God's grace, in word and deed, when it is most needed. The communion and equality of baptism means that wherever we may be in the world, we share the calling to let the reality of baptism shape our lives in a tangible sense. This is a Christian justification for involvement in issues being discussed in society. Others have different reasons, but we all share the call to compassion and care.

Fellowship and community of various kinds thus shape both the view of human beings and the understanding of God. Belief in the triune God means that fellowship also exists within God's self. Relationships are characteristics of both the human and the divine.

Freedom and responsibility

The freedom Christian theology defends is not the same as full independence from others, a freedom *from*, but instead is a free-

dom *to*. Martin Luther argues that freedom is twofold in his treatise *On the Freedom of a Christian*. Human beings are free due to being loved by God, and this gives them the freedom to serve others.

The first freedom is closely related to Luther's reformatory discovery: that human beings are justified by faith alone, not by their own deeds. Luther emphasises that when a person hears the liberating message of Jesus Christ, God can awaken in them a trust that leads to liberation from sin, guilt and death.

The second freedom comes from the love of Christ awakening human beings to live as God wants, and God wants us to love one another. The Christian is therefore liberated by faith to act with love towards their fellow humans. Everyone wants to be, and may be, a Christ for others. The Christian tries to help others, not to make God approve of them and reward them with the forgiveness of their sins and eternal life, but because God gives them these through faith.

It is part of the greatness of human life that we have this freedom to take responsibility both for others and for ourselves. The freedom to choose means that people can come to different conclusions. At the same time, this freedom also requires support from those around us. There is a need for good communities in the church and elsewhere in society, where people can explore what the freedom to take responsibility ultimately implies. Together we can gain deeper insights into how to take responsibility for each other and foster the ability to determine what is

good and right. The freedom to take responsibility therefore also has a societal dimension.

Righteous and sinners

We have been made righteous. At the same time, doing wrong is inevitable. Sometimes we make mistakes; sometimes we do what we know is wrong. This is described by Paul in Romans 7 as doing not the good we want to do, but the evil we do not want to do.

A key point of departure for a Christian view of human beings is the atonement in Christ and the salvation and eternal life that it has brought. This conceptual pair can therefore be said to encompass the other three pairs. We will repeatedly fail to strike a balance between recognising our limitations as created and our opportunities as co-creators. We are fighting an uneven battle between using our freedom and taking our responsibility in a good way. As persons, we can both fail to stand up for ourselves and isolate ourselves in destructive ways from the community. As a community we can be supportive, but also restrictive and oppressive. When we fail in relation to the three conceptual pairs previously described, it is often because we sin in a theological sense and turn away from God. Confessing sin and receiving forgiveness is a gift to live by that provides courage and strength.

Evangelical Lutheran theology emphasises that humans are simultaneously righteous and sinners. We will never be perfect, but can always start again. Our mistakes and guilt are embraced by God's love, which empowers us to live with and pursue our

ideals. Humans have both their origin and their end in God.

The fact that we are both righteous and sinners provides us with perspective on how to deal with the specific choices we have made regarding the questions we have faced about the beginning and the end of life. This conceptual pair identifies how we can live with the choices we have made. The choice may feel wrong in retrospect, it may be questioned by others or leave us with uncertainty as to whether we should have done things differently. Grace empowers us to have the courage in our lives to move on from what went wrong, or to move on despite uncertainty about whether in fact we made the right choice. God's grace bears us, regardless of what life may bring.

A realistically hopeful view of empowered human being

The theological understanding of the human being we have outlined is both hopeful and realistic. The basis of hope is God's care through Jesus Christ – a care for all human life and what it encompasses. This view of humanity goes beyond naive optimism and cynicism. It is neither unequivocally positive nor negative. It states that we have an ability to be morally competent. Our failures and our sin do not deprive us of this competence, but the awareness of this requires us to show humility in the face of error. By receiving God's forgiveness, we are empowered to start over and do things right.

This empowerment of the individual is central to the Evangelical Lutheran tradition. We all have the ability and a

responsibility to reflect and make decisions on ethical issues. Sometimes we make mistakes, and there needs to be the possibility of reconsidering our position.

The theological notion of 'Law and Gospel' is one way of describing this. Complying with the 'Law' in this context means following God's will and is thus a broader concept than legislation. Ethical requirements persist, even when we as humans are unable to live up to them. The Gospel says that grace is given and that it provides both the power and the freedom to continue striving to achieve the ideals of a good society. Receiving the gift of life or God's love is therefore not conditional on us striving to do what is good and right. Rather, opportunities to follow God's will and to do good stem from human gratitude for having been given life. Through God's forgiving love, we receive the grace that gives us renewed strength to continue to protect every fellow human as made in God's image and thus safeguard a good society for all.

In Christian theology, human life is seen as embedded in a context that extends beyond the limitations of the time and space of earthly life. The resurrection shows that not even death can set limits for God's care. The eternal perspective is also important in relation to the ethical issues that arise at the beginning and the end of life. We have been promised that neither death nor life will be able to separate us from the love of God that is in Christ (Romans 8:38–39). This is a source of hope in all situations in life. However, it does not exempt us from taking responsibility in the here and now.

Christian faith means trusting that God never abandons any human being, and that God supports us in our endeavours to do good and to do the right thing. Believing in the resurrection is not the same as being naively optimistic. Rather, it is about trusting in the God who promises to carry us through the various forms of death in the journey of life, on to new hope and new life.

II Ethics based on Christian faith

Ethics are not the exclusive domain of the church. The Church of Sweden is an interpretive community, and dialogue with other actors in society is a fundamental aspect of its identity. The role of Christian ethics is not to provide simple answers to complex questions, but to contribute to the discussion of issues regarding the beginning and the end of life based on its own points of departure.

The reflection that is distinctive of ethics based on Christian faith is not unequivocal or static. Nor is it separate from other forms of ethical reflection but is shaped in dialogue with other views of life, scientific theories and current societal issues. We draw from multiple sources, and ethics are always shaped within a context.

The Evangelical Lutheran tradition recognises that there is much that unites people and that everyone can and should engage in discussions about what is right and good. Together we are responsible for establishing and maintaining good order. This can be seen as an expression of ethics based on Christian faith being rooted in creation and in what is universally human. At the same time, the message of love found in the life and work of Jesus is also

crucial to ethics. This means that ethics are rooted in creation, as well as in Christology and eschatology. We thus emphasise the ability of all human beings to gain insight on moral issues through the perspective of creation, while at the same time highlighting the unique contribution of Christian faith to ethics. Uniqueness does not imply superiority, but instead concerns interpreting ethics in the light of Christian tradition, often clarified by passages in the Bible and the patterns we see in the stories about Jesus.

In encounters with different traditions and their specific ideas and beliefs, there is always an opportunity to learn something new, which can help to broaden and enrich one's own views. We seek answers to existential questions together with others who do not share our faith. Questions about the beginning and the end of life are not only for the individual. God's creation of the world means that all human beings share the basic conditions of life, as well as responsibility for the world and each other.

Many sources of Evangelical Lutheran ethics

How do we acquire knowledge of what is right and good? There are different perceptions of what constitutes sources of ethics based on Christian faith, what weight the sources of ethics should be assigned in relation to each other and how they should be related to other sources. This is why Christian traditions differ to some extent regarding questions of the beginning and the end of life. Most traditions recognise that there are more sources than the Bible. Christian tradition serves as a guide while also

embracing diversity. Knowledge of different scientific theories and results also plays a key role. People's concrete experiences serve as another source.

In the Evangelical Lutheran tradition, the Bible has a special position as the norm of all norms, but it does not provide definitive answers to all questions. Nor is it the case that every commandment and ordinance that appears in the various biblical texts has a direct bearing on contemporary Christian ethics. One well-known example is that there are passages that clearly state that women should be subordinate to men, as well as those that promote gender equality (Colossians 3:18, Galatians 3:28).

In this context, differences between and within different Christian denominations regarding how they view the Bible come into play. Where our tradition is concerned, it is important to identify the core of the Bible and to take responsibility for one's interpretation of the Bible by explaining one's choices. At its core are stories of the life, teaching, death and resurrection of Jesus. The double commandment of love occupies a special position: that you shall love God above all things and your neighbour as yourself (Matthew 22:37–39).

At the same time, the biblical message of love has been interpreted in different ways in different concrete situations throughout the history of the church. The church transmits a living tradition, one that has evolved over time and in relation to different settings. We have access to good standpoints and can learn about the arguments and considerations that led to them. But the

paths of tradition are rarely straight, and sometimes they lead us astray or to a dead end. Tradition must be handled responsibly – critically and self-critically. Even in a church, it is important to learn from mistakes.

One example of the church's restraint is its view of suicide. There was a time when those who had committed suicide were buried outside the cemetery walls, as it was considered a particularly grave sin to take one's own life. Today, such a practice and such an approach are alien to the church. We have a different kind of knowledge about mental health and want to provide support and assistance. We want to provide care to those who harbour dark thoughts and are unable to cope with their lives. We mourn those who take their lives and provide support for their families.

Need for ethical principles

How do you move from a view of human beings and theoretical considerations to informed choices? For example, based on the above reasoning, are abortion and assisted dying right? This letter has so far focused on the theological basis for answering questions of this kind. Through the different perspectives of the four 'both/and' conceptual pairs that we have used here to characterise a Christian view of human beings, we have specified our basis for ethical reflection: we see human beings as **created** and **co-creators**, emphasise both **person** and **community** and we are both **free** and **responsible**. An Evangelical Lutheran view of human beings is also characterised by the conviction that we are both

righteous and sinners. We have summarised this as "a hopeful, realistic view of human beings". We have also clarified how we see ethics based on Christian faith relating to ethics from other perspectives.

The risk, however, is that the discussion will either focus solely on a fundamental view of human beings or solely on the specific questions. Tools are required that provide clearer guidance on how the specific questions should be answered than a view of human beings does, taken on its own. Without such tools, the path from the basis of the positions taken to a specific view becomes unclear, perhaps solely intuitive.

It is also necessary to be able to reflect on issues such as abortion and assisted dying with people who have different points of view and do not see human beings as either created or co-creators. They may have different ways of expressing their views on the limitations and opportunities, autonomy and social contexts, freedom and responsibility of human beings. There are also other ways to describe and relate to the fact that people do both right and wrong.

The tools we will now present are four ethical principles that guide action and enable ethical reflection. Each of them is closely related to the four perspectives on a Christian view of human beings that we have presented. This applies to the first three conceptual pairs explicitly, and the fourth implicitly. As previously stated, the conceptual pair of righteous and sinner can be said to encompass the other three. We will therefore return to that pair of

concepts in the conclusion of the letter.

We have chosen to express the principles using concepts that also appear in other contexts, but the clarifications are characterised by the arguments we have presented so far. The principles can also be said to express basic patterns that we can see in the stories about Jesus. Whoever uses the principles will have tools to understand and assess in greater depth situations in which it is necessary to make a choice and act upon it. This is true both professionally and privately, for society and for other communities.

It is also helpful to be able to refer to the principles when engaging in dialogue, both on the content of the principles and on the issues concerned. In order to engage in dialogue, participants need to be able to articulate their positions in a way that others can understand. In this way, it will be possible to engage in dialogue both with those who take different principles as a starting point and those who wish to use the principles in a different way. Despite differences, it is then both possible and imperative to discuss ethical issues and arrive at informed decisions.

The ethical principles we present are partly different in character and may also conflict with each other. They do not provide an automatic answer, for example, to the question of when abortion is justified or whether assisted dying should be defended or rejected. The principles do not always make it easier to make ethical decisions, but they make the path to the decision clearer.

Each person's freedom and responsibility to make decisions

Before presenting these principles, we would like to emphasise that the Evangelical Lutheran tradition highlights the freedom and responsibility of each person to make their own decisions. Therefore, the focus of this letter is more on the foundations and tools than on specific positions. At the same time, we provide examples of how the principles can lead to specific positions being adopted. Through its General Synod, Central Board and Bishops' Conference, the Church of Sweden has adopted positions on various issues concerning the beginning and the end of life. This often takes the form of a response to a motion in the General Synod or a comment on a government inquiry. For example, the view of abortion has been raised several times in the General Synod, while the view of assisted dying has been discussed in other forums. The questions are then limited to a certain aspect of a larger ethical issue or are of a more general nature, where the format does not allow for in-depth argumentation. In this letter, we expand upon the underlying ethical and theological arguments for such positions.

The principle of human dignity

The conviction that each person is **created** by God and in God's image is fundamental to a Christian view of human beings. When we speak of human beings as the image of God, we emphasise our unique relationship with God, our inseparable affinity. The deepest potential or purpose of human beings is fulfilled in their relationship with God. God loves all of creation but has a special

relationship with human beings, a relationship that Christian faith helps us explore and deepen.

The conviction of the dignity and inviolability of human beings, a unique worth that each person has precisely by virtue of being a human being, forms the basis of the principle of human dignity. The conviction that every human being is created in the image of God is the theological reason for the requirement to care for one's fellow human beings, a requirement which is not limited by age, health or any of the other categories we use to distinguish between people. Every human being should be respected. Human dignity is also independent of what the person does or achieves. The roots of this principle can also be found in the parable of the Good Samaritan (Luke 10:25–37). The story concretises what caring for every human being means.

In an argument with an expert in the law about what loving your neighbour means, Jesus responds with a parable about a man lying beaten by the roadside. Two people who could be expected to help just pass by. The person who was not expected to intervene, the Samaritan, helps. He treated the beaten man as a person, recognising his humanity along with their common humanity, and helped him even though it may not have been in accordance with the prevailing conventions.

Human dignity establishes limits for how we should behave towards others and expresses respect for the integrity of the individual person. Therefore, nobody has the right to exploit other people for their own purposes. We should always see each other

not only as means, but also as ends.

The principle of human dignity thus requires us to refrain from actions that may harm or wrong other people. It also indicates what we should do. It requires us to work actively for others, to protect their rights and well-being. In this way, the view of human beings as **co-creators** is also expressed. We have a duty to use our abilities to reduce the suffering of others and safeguard their health.

The principle of human dignity is often interpreted in medical ethics primarily as a principle of respect for autonomy, the principle of autonomy, which states that people have the right to exercise self-determination. Self-determination in healthcare means that patients should have the opportunity to make their own decisions about their lives. In concrete terms, this entails a requirement for informed consent, whereby patients must be given information about their health status and the possible treatment options available.

We also believe that it is important to safeguard people's right and ability to make decisions about their own lives. But self-determination and decision-making never take place in a vacuum. Human beings are **persons in community**. We are created in and through relationships; our decisions also affect others.

When faced with challenging ethical questions, we need communities where we can seek meaning and deeper spiritual understanding while reflecting together. Such conversations also enable us to understand better what our independence – autonomy –

means. Each person's possibilities and limitations are shaped in relation to other people and to the contexts they are part of. We are both autonomous and relational. We have a responsibility in relation to ourselves and to others to reflect actively on the choices we wish to make and how they affect people in our surroundings. This is also true of life's critical moments.

Respecting the value and dignity of human beings also means recognising our capacity to act with moral competence. We have **freedom to be responsible**. Responsibility is individual, but the community is a resource. We can make use of the ability of others to reflect on morally complex issues. To be able to make informed choices, we need to be able to take in and relate to more aspects than those we initially see ourselves, enabling us to recognise the complexity of different situations. This requires support from those around us – we need to talk to others in order to clarify where we stand and challenge habitual patterns of thinking. Moral competence means being able to navigate through life from a holistic perspective. The bigger picture helps us use our freedom to take responsibility.

Respect the value and dignity of every human being.

The principle of responsibility

Another key tool for questions regarding the beginning and the

end of life focuses on responsibility for fellow human beings – the principle of responsibility. We often talk about 'the vulnerable' as if it is about other people, but it is about all of us. The principle of responsibility is universal, even if it varies in its application due to there being different types of exposed situations. This principle also draws attention to different types of power structures that can perpetuate the vulnerability of groups.

The principle particularly applies when a person or group cannot speak for themselves. How a society deals with the exposure that affects people in terms of limiting their ability to act is crucial to ensuring everyone's security and trust. We are all dependent on the knowledge that there is someone who sees and safeguards our value even when we are at our weakest. This is an existential cornerstone of a democratic society.

In our interpretation of this principle, the view that vulnerability is a condition of life is fundamental. To be vulnerable is part of the limitation of being **created**. We are all vulnerable to different degrees at different times or in different life situations. Vulnerability affects to a greater degree those living with severe illness or disability. This demands our attention, ensuring that we really take responsibility for the vulnerability of others, and in so doing our own vulnerability.

Human beings are both strong and weak. As **persons who are part of communities** – both close to us and at a societal level – this is something we constantly have to navigate as well. Our **co-creating**, the use of our creative abilities, needs to take

into account that there are times when freedom is severely limited. There are structures that make it difficult to end the state of vulnerability and instead perpetuate the vulnerability of certain groups. Vulnerability therefore makes our responsibility for each other clear and imperative.

Protecting on each occasion those who are weakest, those who are in an exposed situation for one reason or another, is a clear point of reference to use as a tool for ethics based on Christian faith. Jesus equates caring for the exposed with taking the Gospel seriously and translating it into action: "Truly I tell you, just as you did it to one of the least of these brothers and sisters of mine, you did it to me." (Matthew 25:40).

We all share a common responsibility to ensure that societal structures and legislation are designed with the protection of those in particularly vulnerable situations in mind. This applies to the unborn child and the pregnant woman; to the person who is waiting for an organ and to the person who, after their death, will be the donor; to the terminally ill person who wants to live and to the terminally ill person who wants to die.

At the beginning and the end of life, our basic human vulnerability is particularly evident. We are then also forced to recognise how dependent we are on others. The particular vulnerability that can arise in life's critical moments, such as severe illness, requires some people to use their **freedom** and take **responsibility**. For example, if I have ALS, others may interact with me in an inclusive or exclusive way. The people I encounter may see me as a person in

relation to them or as a neutral individual among others. Vulnerability is an existential condition of life, but responsibility for others is especially applicable when someone is in a particularly vulnerable situation. Vulnerable voices and perspectives need to be heard in the public debate on how society can best protect all its members. This is where our ethical compass is put to the test.

Take responsibility for your fellow human beings, especially when they are at their most vulnerable.

The principle of the best interests of the child

Children have a special place in Christian faith. When Jesus blesses little children he says: "Let the children come to me; do not stop them, for it is to such as these that the kingdom of God belongs. Truly I tell you, whoever does not receive the kingdom of God as a little child will never enter it." (Mark 10:14–15) The way children relate to those around them also teaches us about how we should act towards our fellow human beings. But the openness and trust that children show also makes them particularly vulnerable to betrayal and abuse by the adult world. The best interests of the child should be the guiding principle. The exposed situation of children is also reflected in the fact that they sometimes find it difficult to make their voices heard. With the Convention on the Rights of the Child becoming Swedish law on 1 January 2020, children's

rights have been reinforced both in society and in the church. Throughout history, the view of children has shifted towards seeing the child as a subject in their own right, with potential to develop. The child is a person undergoing major changes – physically, mentally, socially and spiritually. There is thus a dynamic of being a **created co-creator** in both children and adults. Jesus presents the child as a role model. Viewing the child as a created co-creator implies an obligation to take the child's experiences seriously.

A child's ability to manage their **freedom** and to take **responsibility** depends on their maturity. The freedom and responsibilities of a four-year-old are more limited than those of a twelve-year-old. At the same time, we recognise that the rules for different ages we set in different contexts do not follow any laws of nature; they are instead the result of what society has collectively deemed to be reasonable limits.

Children are **persons** who are part of **communities** with adults. Children need adults to safeguard their best interests, to ensure that their perspectives are expressed. It is important to listen to children when the family is unexpectedly faced with the question of donating the organs of a parent who died in an accident. The legislation does not allow for a veto by relatives, but it does state that society must protect children's best interests. Safeguarding children should always be the guiding principle.

Many of the situations that can arise at the beginning and the end of life set different interests and values against each other. As

with all genuine dilemmas, there is no simple answer to what the right balance of interests is. However, what is in the best interests of the child should always be a major consideration when deciding what should be done or which alternative course of action to take.

Let the best interests of the child be the guiding principle.

The principle of justice

Questions about the beginning and the end of life also concern how we view society and our shared life as **persons in community**. What kind of society do we want to create through legislation, institutions and innovations? What lives will be possible within this society? Who will benefit from it? It is also about how we use our **co-creative** capacity and manage our **freedom and responsibility**. In the case of the principle of justice, the different perspectives in the view of human beings are particularly closely intertwined.
The golden rule makes far-reaching demands of us:

> In everything do to others as you would have them do to you, for this is the Law and the Prophets.
> *(Matthew 7:12)*

When we read this and consider specific applications, such as the extent to which the involuntarily childless should be given assis-

tance, we realise that the answer to the question of what is just is not a simple one. Costly interventions for those who depend on extensive support for their own lives need to be balanced against interventions that help others.

The rapid development of biomedicine offers tremendous opportunities to cure and prevent disease and ill health as a result of people's creative abilities. At the same time, there is a risk of aspects of what it means to be human becoming obscured if we expect technology to enable a perfect life, a life without the experiences of illness and disability. Expectations of what life should mean affect our societal norms, and this is something we need to take responsibility for in discussions about what medical treatments should be permitted.

We are interdependent. This means that we are responsible for creating a society in which all people are given equal opportunities. How does this happen, and what guarantees does society need to give its citizens so they can feel that it is both possible to make independent decisions and to stand up for and take responsibility for them? These are issues that need to be addressed as a society. They also include matters of prioritisation that form part of the reality and everyday life of healthcare, where it is important that interests are balanced on reasonable grounds and in a transparent way.

Work to build a just society.

III Ethical reflection on questions about the beginning and the end of life

We have now characterised a Christian view of human beings on the basis of four perspectives. Human beings are **created and co-creators, persons in community, with freedom and responsibility**. These three perspectives are encompassed by the view that human beings are both **righteous and sinners**. Grace frames the human condition.

The view of human beings has led to four guiding principles being identified as tools for ethical reflection: **the principle of human dignity, the principle of responsibility, the principle of the best interests of the child** and **the principle of justice**. How do they help us make choices on different issues?

Even if we take these principles as starting points, it is important to be humble in the face of the challenge and uncertainty that are always associated with making choices regarding complicated medical ethics issues. In pastoral care, priests and deacons in the parishes of the Church of Sweden meet people struggling with concrete choices.

In light of this, we will now address four questions concerning

the beginning and the end of life. In the introduction, we stressed that the presentation of the specific examples we provide is limited. We have only been able to indicate briefly the variety of different circumstances surrounding issues at the beginning and the end of life.

The beginning of life

The beginning of life encompasses a wide range of conditions and situations. It includes wanted pregnancies alongside unwanted ones, voluntary and involuntary childlessness, women's rights and children's rights. Hospital chaplaincies and other providers of pastoral care for individuals in parishes are well acquainted with the many aspects. Conversations about the issues raised often take place in confidence, but they are also discussed in newspaper debates and in social forums. Issues are dealt with quietly and privately, or loudly and publicly. We recognise that this is not enough. One of the church's missions is to make space for respectful dialogue in which the principles can be applied and tested.

Developments in recent decades have pushed back the boundaries of medicine in ways that previous generations could never have imagined. The technologies available today raise questions in a partly new way about what should be considered the beginning of life and the point at which human dignity comes into play. According to the UN Universal Declaration of Human Rights, human rights also include the right to found a family. Article 16:1 states:

> Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family.

At the same time, we need to ask ourselves what our reproductive rights include and which of the various paths to parenthood are ethically defensible. When discussing these issues, it becomes clear that biological facts do not provide definitive answers. People come to different conclusions, but we all have a responsibility to justify our positions as best we can.

Another change concerns family building in general. Families take many different forms. Legislation has also made several more types of family possible than before.

The principle of human dignity requires that all parties involved are respected. **The principle of responsibility** raises questions about how to address the vulnerability that is a condition of life for all people. **The principle of the best interests of the child** applies to both the expected child and other children affected. **The principle of justice** raises the question of society's responsibility for the needs of a child born with a serious illness. The different principles may also conflict with each other.

Foetus or child?

When we reflect on questions regarding the beginning of life, the choice of words is important. Is it a foetus or a child? There are medical definitions of when an embryo becomes a foetus and a

foetus can be called a child, which form the basis of healthcare practices and the legislation that underpins them. But there are also existential dimensions that are important, particularly in the case of terminated pregnancies.

One example of when the existential dimension may be important is during an early miscarriage. There may be a desire and need for parents to talk about the child they lost. Even in the case of an abortion performed after serious foetal damage has been detected, parents may want to talk about the loss of their child. When the reason for an abortion was that the woman did not wish to become a parent at this point in her life, she may also want to talk about the child that will not be born. For others, it may be important not to use the word child, but to speak of a foetus, in such an abortion.

In this respect, pastoral sensitivity and a sense of what is the right term to use when encountering people who have had an abortion or miscarriage are very important. It is vital to recognise that abortion is a morally charged situation – without apportioning blame. A person who chooses to have an abortion should not be assumed to have certain thoughts or feelings. Many people who have had an abortion testify that it was the right decision, while at the same time being an experience that affects them on an existential level. The experience may remain with them throughout their life and may be associated with grief. The right of women to make decisions about their bodies and lives, such as whether or not to become a parent, must be met with respect. This is what it means

to treat all people as morally competent.

In this section, we will concentrate on the issues of prenatal diagnosis and abortion. Many people are faced with the concrete choice of whether or not to continue a pregnancy. An unwanted pregnancy raises one set of questions about what is right and good; a wanted pregnancy that cannot be carried to term for various reasons raises somewhat different questions.

Prenatal diagnosis is regularly offered to pregnant women today. Let us take this as a starting point. The woman or couple intend to carry a pregnancy to term. This does not necessarily mean that the pregnancy was wanted or planned from the start. People faced with the possibility of prenatal diagnosis examine the issue from different perspectives.

Prenatal diagnosis

Prenatal diagnosis involves several methods that can be used at different times during pregnancy. The tests used are ultrasound, combined ultrasound and biochemical test (CUB), amniocentesis, placenta test and, in some places, non-invasive prenatal testing (NIPT). The latter is done by taking a blood sample from the pregnant woman and analysing the foetal DNA it contains. There are now several methods for examining chromosomes and genetic predispositions shortly after fertilisation. The longer a pregnancy progresses, the greater the chances of detecting diseases in and damage to the foetus.

Prenatal diagnosis can be used to determine the length of pregnancy and the number of foetuses, to assess the health of the foetus, to detect certain disorders or damage, and to examine the placenta and the amount of amniotic fluid. These tests can provide important information that can help promote foetal and maternal health. They can also contribute to techniques that can provide information on most conditions for which there is no known cure or treatment. Essentially, the entire genotype of the foetus can be mapped and predispositions for possible future diseases detected.

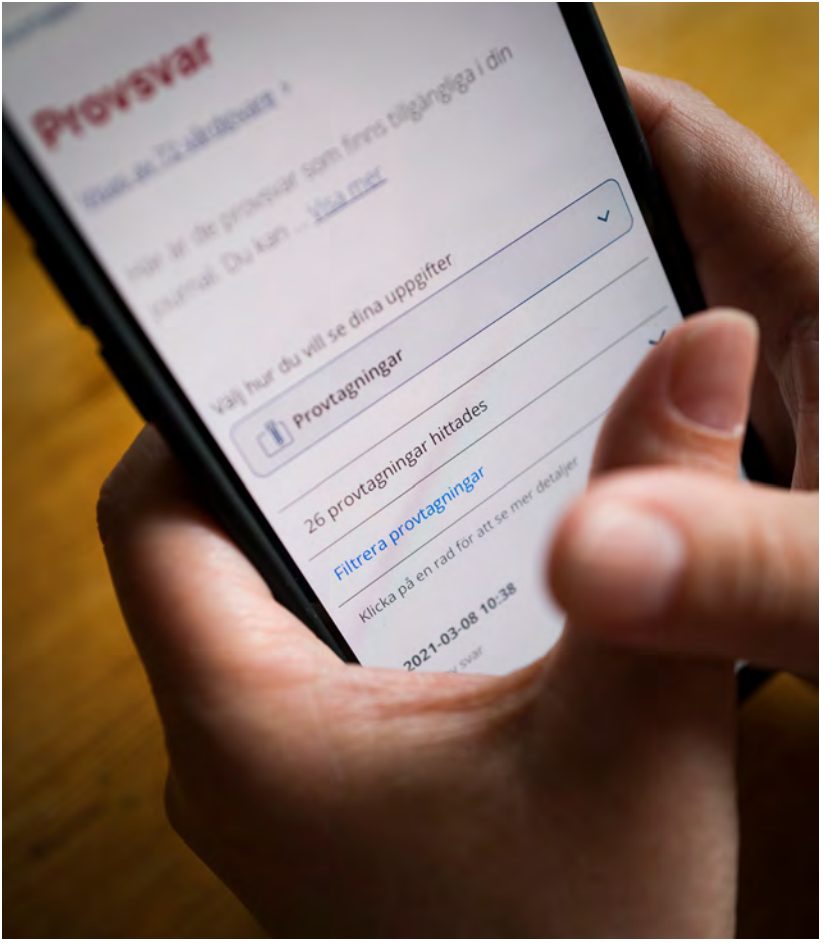
Undergoing prenatal diagnosis is voluntary. Those who choose to undergo prenatal diagnosis may receive information that is used to promote the health of both the pregnant woman and the foetus, but also to make decisions about terminating the pregnancy.

The offer to undergo prenatal diagnosis presents people with the choice of receiving information about the foetus or refraining from learning more. The Church of Sweden has not taken an explicit stance on the issue of prenatal diagnosis, nor has it distanced itself from this possibility. Anyone who chooses to undergo prenatal diagnosis may receive information that is not easy to relate to. What is the risk that predisposition for a particular disease will actually cause the disease or disorder? And if the parents-to-be learn that the foetus has a serious illness, is this a reason to terminate the pregnancy?

In a situation where the parents-to-be or the single woman find out that the foetus has a serious illness, this raises several urgent

questions. **The principle of human dignity** not only safeguards the healthy, but demands that every human being be respected. Human dignity applies to every person, regardless of special circumstances and needs. Everyone has something to contribute to the community through their existence. At the same time, the parents-to-be are faced with a choice concerning a foetus that is not yet fully developed. The Doctrinal Commission of the Church of Sweden has emphasised that there is a relevant difference between a foetus, which is "a human being in the making" and a child (Ln 1993:513). We will come back to this difference later on. In this context, an abortion may be considered. However, for the parents, the focus can be on the future human being in a way that assigns the principle of human dignity a great deal of weight. The expected human being is seen as a person who is already part of a community.

The principle of responsibility requires us to take responsibility for our fellow human beings and not to abandon them, especially when they are at their most vulnerable. Living with a serious illness and the severe limitations that disability can entail is living with constant vulnerability. At the same time, illness and disability are never the whole person. Each human being is a gift to others. We also bear responsibility as a community not to foster false notions or wishful thinking that the perfect life exists. We all struggle with difficulties of various kinds. When someone suffers a stroke, considerable resources are mobilised to save their life, even if it may be limited by permanent damage.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Research shows that there is a big difference between how healthy people value life with a serious illness and how the seriously ill themselves do. Healthy people imagine that their life would be worth less if they themselves were ill. However, people with serious illnesses can also feel that their life is worthwhile and brings them joy. The focus shifts from being centred on life goals and survival to values that are of a different character and concern the near future.

People living with disabilities emphasise that an increase in the number of abortions due to the information provided by prenatal diagnosis also means a change so that they are viewed more negatively. When lives with severe limitations are seen as something that can be avoided through selective abortions, welcoming children with severe disabilities into the world can seem like an irrational choice. Economic issues also quickly arise. What is the reasonable cost of a life? This kind of shift in values regarding disability implies a shift in how people view vulnerability, which risks appearing more as a choice than as a condition of life.

The principle of the best interests of the child requires that children are given favourable conditions. At the same time, these always vary in relation to a range of factors, such as social and economic ones. Parents-to-be who have to decide whether or not to continue a pregnancy need to do so based on their values and an assessment of their social and economic situation. Perceptions of what makes life worthwhile may also change in the face of such a decision. Living with limitations affects siblings and the life of the

whole family.
Knowing that the expected child has a serious illness may in itself be perceived as contrary to the best interests of that child. Because the parent or parents find this out at an early stage, the foetus is not yet a child and abortion can therefore be both ethically justifiable and legally possible.

If there are other children in the family, their best interests should also be taken into account. A sibling who requires extensive care means a major change in the other children's circumstances. Parents will need to pay special attention to the child who has special physical needs or difficulty coping on their own. Receiving personal assistance means that additional people will take their place within the family sphere. Family life will be different than it was before.

A negative answer to the question of whether to abort a foetus with a serious disease implies a different approach to the best interests of the child. Every child is different, and the principle of the best interests of the child means endeavouring to safeguard the child's welfare in every situation. This also applies to children with serious illnesses. Children living with someone with special needs see a side of life that not everyone sees. This provides perspectives that challenge norms of development, independence and success as being desirable. Carrying a pregnancy to term in the knowledge that the child has a serious illness is also consistent with the best interests of the child. At the same time, such a choice leads directly to issues related to the principle of justice.

What support systems are in place to accommodate the child? Medical developments with the possibility of prenatal diagnosis also mean that those who choose to continue with the pregnancy may experience a different type of questioning from those around them than before. They may feel that they need to defend their choice, and that the offer of prenatal diagnosis was not actually an offer, but rather there was an expectation that a negative result would lead to an abortion.

Finally, **the principle of justice** means that society must provide the support necessary to ensure that a life with severe limitations is well cared for. Even if parents are prepared to give all the support they can, they also depend on society taking responsibility. For parents-to-be to feel that it is possible to welcome a child with disabilities of varying degrees into the world, there need to be robust support systems and opportunities for help and respite. Whether they feel it is possible to parent a child with disabilities should not be determined by financial considerations. At the same time, there is often a gap between ideal and reality.

The choices made when a foetus is diagnosed with a serious illness are influenced by what is desirable and possible in society. In concrete terms, the choice is influenced by the help available to a child with special care needs. Indirectly, the choice is also influenced by the attitude of society towards people with different forms of disability. The struggle of relatives for the rights of people with disabilities can be hard to bear. Stories of what societal support makes possible for people living with severe limitations

can provide hope. Society's various institutions and systems can be designed so that people with different disabilities can participate equally.

In Sweden, abortion is unrestricted until the end of the 18th week of pregnancy. After that, the pregnant woman who wants to have an abortion must apply for special authorisation. The application is examined by the Legal Advisory Board of the Swedish National Board of Health and Welfare, which decides whether there are special reasons that can justify an abortion. The current practice is that abortion can be authorised up to and including week 21 of pregnancy. This practice is based on the fact that abortion cannot be authorised if the foetus is likely to survive outside the pregnant woman's body and that, in some cases, it is now possible to save babies born in week 22 with considerable medical interventions.

From an ethical and legal perspective, there is a tension between the right to protection of the foetus and the rights of the pregnant woman. The Swedish Abortion Act prioritises a woman's right to her body. The foetus is considered to have rights to protection that increase as it develops towards being able to live outside the womb. In Sweden, the upper limit for abortion has been set according to when the foetus can be considered viable, and anyone born from the 22nd week of pregnancy onwards is considered a child.

Unrestricted abortion up to 18 weeks and regulated abortion up to the viability limit is an attempt to manage the tension between the interests of the pregnant woman and those of the foetus.

At the same time, society aims to reduce the number of abortions

by giving people better opportunities to protect themselves and avoid unwanted pregnancies. Society should also help those people who have not planned to become parents but who have a desire to carry a pregnancy to term. Overall, this indicates that abortion is not seen as unproblematic, or that the fact is ignored that deciding whether to choose abortion involves an ethical dilemma in which strong interests are set against each other.

Abortion

The issue of abortions after negative results from prenatal diagnosis, as discussed above, shows that abortion can be about medical facts. At the same time, abortion legislation has a general character, with abortion being an option for every woman who becomes pregnant.

The principle of human dignity is central, as we have seen in the case of prenatal diagnosis. A crucial question is therefore when the foetus is viewed as a person. Many Christians believe that human dignity exists from the moment of conception and do not accept abortion at all, or only in certain exceptional cases. The latter may apply when the mother's life is in danger.

As mentioned, a foetus in early pregnancy is described as "a human being in the making" in the opinion of the Doctrinal Commission 1993:513. The rights of the foetus increase the longer the pregnancy progresses. The Church of Sweden's position is that abortion is acceptable because there is a crucial difference between a foetus and a child.

The legal threshold for abortion is based on viability. Today, it is estimated that in some cases, with major medical interventions, children can be saved from week 22. Scientific knowledge provides a basis for making judgements and is the most reliable source we have for distinguishing between foetus and child. When discussing these thresholds, balanced ethical reflection is crucial. The right of women to make decisions about their bodies and lives, such as whether or not to become a parent, must be met with respect. Ethical reflection needs to include responsible consideration of the human dignity of all concerned.

The existential dimension of the question of when human life begins also plays an important role for the individual. It is one thing for society to set limits regarding when abortion is an option, limits that define the boundaries within which decisions to continue or not to continue a pregnancy can be made. Personal experience of the pregnancy is another, equally important dimension.

The principle of responsibility points to the fact that we have a shared responsibility for managing life's complications. Unwanted pregnancies happen all the time, and it is important that women are not left without choices in such situations. Women may also be pressurised not to continue with the pregnancy. The fact that the woman has the right to decide whether or not to have an abortion does not mean that she alone is responsible for the pregnancy. Her partner has a special responsibility. Other people close to them can also have a major impact on the decision the pregnant woman is able to make.

The ideal is that abortion should not be a necessary option. Access to contraception and good opportunities to have children in a variety of circumstances counteract the need for abortion. However, it is utopian to imagine a world completely free of unwanted pregnancies. Those most severely affected are those in exposed situations such as poverty and social deprivation. There are also other situations in which access to safe abortion is necessary.

In many countries, access to contraception is very limited and the chances of creating a good life as a single mother are slim. It is common for single mothers and fatherless children to be looked down upon. Many women lose their lives in illegal abortions.

A Christian view of human beings emphasises that human existence involves both freedom and responsibility, both autonomy and vulnerability. The church has a role to play in supporting those who are agonising over a pregnancy and its consequences for themselves and those around them. It is important to provide support for the woman who is faced with the choice of whether or not to continue with a pregnancy. Regardless of what she chooses, the church should also be there to support her and her partner or people close to them afterwards. Doing so is a consequence of the Christian calling to meet people where they are and to take their lives and human vulnerability seriously.

The issue of abortion also has a social dimension. **The principle of justice** seeks to ensure that society is organised to welcome parents and children with varying circumstances. Single women

with children are better off today than in previous generations in terms of economic opportunities and social status. Yet, as a group, they live more exposed than others. This affects their ability to feel secure in accepting children who were not initially planned or wanted. Abortion is not the only option, but it may appear to be.

The question of what is in **the best interests of the child** always needs to be asked. In a society that protects children with all their differences in terms of conditions and contexts, the ability of parents-to-be to carry pregnancies to term is also affected.

At the end of life

Death is an existential paradox: everyone will die, but nobody knows when or how it will happen. Death is both a guaranteed fact and something unpredictable.

We learn to live with the death of others. There is a before and an after. It can take time to orientate yourself when your life changes so radically. After a while, those who are left behind often realise that it was possible to move on, that grief has its phases – while new life patterns take shape.

This is not the case with our own death. It can only be managed as long as we live. One issue related to our own death is that of organ donation. If the worst happens and my life cannot be saved, do I want my organs to be donated to others who need them? Everyone is asked to make their wishes known in the Swedish National Donor Register. Organ donation is at the intersection between the onset of death for one person and new opportunities

for life for another.

In recent decades, the question of whether or not assisted dying should be legalised in Sweden has been debated. Many people are engaged in this issue. Talking about it is a way of talking about your own death. The discussion then assumes that some factors are known, that there is a disease that is expected to take a certain course. If I have been told that I have an incurable disease that is likely to lead to death within a limited amount of time, how do I want to die?

How can the principles we have formulated here be used to address the issues of organ donation and assisted dying? **The principle of human dignity** also applies in dying, both when a person is approaching death and when death has occurred. Every person's death should be treated with dignity and respect. **The principle of responsibility** focuses on the behaviour of those around the dying person, the person's social context. Dying can be said to be the ultimate vulnerability in life. People who have been important in the dying person's life are also important at the end of their life. Another aspect of the principle of responsibility concerns professional carers, who are usually present when a person is dying. In the context of death, **the principle of the best interests of the child** draws attention to how children can be involved in the death of others and the importance of them being listened to. **The principle of justice** offers guidance for assessing the conditions provided by society in the context of dying and thus for deciding which options are available for life assistance.

The overall aim of donating organs is to save lives and provide the opportunity for a healthier and richer life for those suffering from serious illness.

In Sweden, just under 200 deceased people donate organs every year. This gives other people a chance of survival and a better quality of life. One donor can give organs to several recipients. However, the number of donations does not cover the need for organs, and every year people die waiting for new organs. Medical interventions to prepare a donor, known as organ-preserving treatment, are now possible. A decision on organ-preserving treatment cannot be taken until there is an independent decision to withdraw life-sustaining treatment, according to current regulations.

There was previously what was called a relatives' veto, which meant that in cases in which a dying person's attitude towards donation was unknown, the family had the opportunity to decide that organs should not be donated. Recent legislative changes have removed this veto. As the law now stands, Sweden is increasingly moving towards a system where it is assumed that the person wants to donate their organs if they have not made their wishes known via a register or to those close to them. In such a system, it is important that this information reaches everyone, so that they can register with the Swedish National Donor Register and/or talk to their family about their wishes. Children under the age of 15 can be registered by their parents or legal guardians. From the age of 15, they can themselves register their wishes in the register.

We can conceive of the following situation:

> *A woman has been told that she has an incurable liver disease. She is thirty-eight years old and has two young children. Her only chance of survival is to receive a new liver. A liver can only be transplanted from a person who dies under specific conditions, often an accident. Within a few hours, relatives of the victim will be informed of the accident, as well as of the possibility of organ donation.*

When organs are taken from a dead person and given to another person, the irreversible death of a person is related to new life possibilities for others. Anyone who is about to receive an organ knows that the new possibilities of life depend on the abrupt end of another person's life. Those who are grieving for the victim of an accident are placed in a serious situation. A deceased family member can be the one who saves the lives of others. For some, this is an opportunity to make sense of the sudden death; for others, the situation becomes overwhelming.

When it comes to a person being able to donate organs to others, the distinction between patient and donor is an important boundary to maintain. Everyone agrees on that. A patient has the right to treatment, but a donor's organs are being prepared to be received by another person. This concerns **the principle of human dignity**. Respect for the intrinsic human dignity of the dying donor is connected to the instrumental value of the dead

person's organs to another person. There is a risk that this boundary may become unclear. It is therefore important that the rules governing the various stages of the donation process are followed and that the process is characterised by discretion and care. This lays the foundations for safeguarding human dignity, but at the same time requires that it is clear to everyone that the decision to end treatment is to be taken first. Nobody should have to fear not getting the treatment they need as a patient. The principle of human dignity requires that everyone should be able to trust that the medical system always considers the person's best interests.

What does **the principle of responsibility** mean in this context? In the case of organ donation, it relates to the vulnerability and interdependency of several people. Responsibility must be taken both for the dying person, who should be given a dignified end, and for those whose quality of life would be significantly improved by receiving organs.

One way to take personal responsibility is to make a decision and express your wishes when it comes to organ donation. By allowing their organs to be used, people take responsibility for their fellow human beings and their needs. However, it is also possible to decline to be a donor, for example for the sake of one's loved ones. This allows them to be with the dying person until the end without any special arrangements being made for the organs to be used. Like other questions about the beginning and the end of life, this one is deeply personal. Our own past experiences of death influence how we deal with the issues regarding our own

dying and that of those close to us.

A Christian view of human beings, as we have seen, emphasises that we are persons in community. The law does not give relatives the right to prevent donation once the person has registered as a potential donor. Nor can they oppose it with any argument other than what is known about the person's wishes. Once a person has made a decision regarding organ donation, the decision must be respected. At the same time, those closest to the person may not have known what the person wanted and may feel there are strong grounds to act differently. From a theological perspective, therefore, there is a potential conflict between the autonomy of the dying person and their social context that the legislation does not take into account.

In the case of possible conflicts between the wishes of the dying person and those of their relatives, it helps if each person's choice is also known by those who may be affected by it. Taking responsibility by registering your willingness to donate or not to donate organs is important, and talking to your relatives about it equally so.

Organ donation is also an opportunity to improve radically the quality of life of several fellow human beings. The mother who needs a new liver is able to continue her life with her children, and the children will have a sense of security that they would otherwise be deprived of. The value of organ donation for recipients cannot be overestimated. It is a part of human co-creation that enables life to change in critical ways for many. It is not about

someone giving their life for another, but about the fact that the life that has ended, for which further treatment is no longer meaningful, can give someone else new opportunities in life. Anyone willing to donate organs is giving their fellow human beings a great gift. However, the decision must be taken by each person individually.

The principle of the best interests of the child requires taking into account that children can be potential donors or have a close relationship to donors and recipients of organs. For parents and others, it can be comforting to know that the unexpected death of a child can also lead to something good for others. But it can also be important to ensure that the circumstances of the child's death are as calm as possible. It can be difficult to take in what siblings want when the whole family is in shock.

The best interests of children should also be taken into account when they are relatives of a potential donor. Their role as such needs to be handled with the utmost care. They cannot be expected to express themselves in terms of the wishes of the dying person or in a way that can be easily translated into ethical principles. However, the principles of human dignity, responsibility and justice can be useful tools for adults when interpreting children's wishes.

It may also be the child who needs a new organ so they can live a good life. In this instance, there is no doubt about what is in the best interests of the child. The application of the principle of responsibility to the situation of a child needing a new organ

indicates that there are strong grounds for adults to donate their organs.

Organ donation can be seen as an application of **the principle of justice**. For those who depend on receiving organs to have the chance of a good life, it is positive that there are laws and other regulations in place that specify the circumstances under which organ donation is possible. The ethical challenges are mainly related to the other principles. They mainly concern the 'how' questions. How can organ donation be carried out in a way that respects human dignity and the needs of fellow human beings? The dignity and needs concern both the potential donors and those who need organs. The same also applies to those close to them. A human being is always both autonomous and relational, an independent subject and part of a social context. The social context, in turn, is both the immediate context and the wider one. Organ donation links the death of one person with the life of another, and they are unknown to each other. This means that organ donation is an application of the commandment of love that does not limit our obligations to those closest to us: "In everything do to others as you would have them do to you." (Matthew 7:12)

Organ donation also occurs between living persons. Sometimes the donor is a loved one, and the interdependency between the person asked to donate and the person who needs to receive an organ needs to be taken into account. It is imperative to answer the ethical questions in such situations as well.

Assisted dying is an ambiguous term that includes both euthanasia and assisted suicide. Euthanasia as defined by the European Association for Palliative Care (EAPC) is when a doctor or other person deliberately ends the life of another human being using medication, following the person's explicit and voluntary request. Assisted suicide is when a person intentionally helps another person to end their life on their own, following their explicit and voluntary request.

The definitions of euthanasia and assisted suicide also delineate what does not constitute assisted dying. The decision to withdraw life support, either in accordance with the patient's wishes or following a doctor's medical judgement, is not assisted dying. Nor is the relief of symptoms as death approaches (palliative sedation). Subjecting a person to an action aimed at hastening death without the person requesting it is also not assisted dying – it should rather be described as murder.

At present, different varieties of assisted dying are permitted in some twenty countries and states in the United States, mainly under the Oregon and Benelux models.

The Oregon model concerns assisted suicide. Doctors have the right to prescribe drugs in lethal doses that the patient then takes on their own. Several formal requirements in the application procedure aim to ensure that the patient's wish for assisted dying is meticulously thought through and permanent. To be granted authorisation for assisted dying, the patient must be deemed to be suffering from a disease leading to death (terminal illness), death must be imminent within six months and the patient must

be deemed to be capable of making decisions.

The Benelux model concerns both assisted suicide and euthanasia. The requirement for a patient to be considered for assisted dying is unbearable suffering that cannot be alleviated by other means. There is no requirement for terminal illness. The Benelux model makes it legal for a doctor to directly end a person's life after they have explicitly requested it. A patient suffering from a mental illness may be granted assisted dying if it is established that the illness causes suffering for which there is no cure.

Palliative care in its various forms is the support that most people at the end of life receive today. It is characterised by an approach that neither accelerates nor delays death, but sees it as a normal process. At the core of the whole process is the opportunity for the patient to live with dignity.

The issue of organ donation is about when life can be considered to have ended and what is possible to do at that stage. Assisted dying issues concern the point at which life is perceived as no longer valuable, or even unbearable.

Feeling that it is impossible to continue living can have both physical and psychological causes. It is thus not just about when death is inevitably approaching. Life can be perceived as having lost its value in completely different situations. It can also be a matter of not wanting to be a burden on family or society.

People living with physical limitations may feel that life is losing its meaning and long to end it. But what is needed may be less about assistance in dying and more about help that makes life

easier and alleviates. It could be called life assistance. These limitations can often be alleviated or compensated for and the quality of life significantly improved.

Mental health problems are widespread in our society. The Benelux model allows individuals suffering from depression or other mental illness to request assisted dying. There is a major risk that the person will make an irrevocable choice instead of seeking care that provides relief and heals. Young people sometimes need help to live, so that they have an alternative to longing to end their lives, life assistance rather than assisted dying.

In recent decades, the question of whether or not assisted dying should be legalised in Sweden has been debated. Not infrequently, the discussion has been triggered by media reports that a person has chosen to use some form of assisted dying, either in Sweden with subsequent legal consequences, or abroad, primarily in Switzerland, which permits assisted suicide for foreign citizens at the country's 'death clinics'.

As in most other major churches in Sweden and other countries, the Church of Sweden has rejected the idea of making assisted dying legally possible in Sweden. A Christian view of human beings and society forms the basis for rejecting assisted dying. At the same time, it is important to show humility with regard to people's different positions and to recognise that there is a difference between giving a theoretical answer to the question of whether to be in favour of assisted dying when a person is healthy, and accepting assisted dying for oneself or together with loved

ones when a person is terminally ill.

What does the principle of human dignity, of respecting a person's human dignity and treating someone accordingly, entail when it comes to assisted dying?

Assisted dying is sometimes described as the best way to preserve a person's human dignity when death is approaching through illness that causes suffering and significant limitations. Knowing that the possibility exists would then be a comfort should it turn out that a person is likely to die in such a state.

Our position is based on the notion that people should respect the person's dignity for as long as their life should last. This also applies to the process of dying itself. Suffering can be said to have four dimensions: the physical, the psychological, the social, and the spiritual and existential. Dying with dignity is about realising the potential for relief in all these dimensions.

The principle of human dignity is theologically rooted in the fact that human beings exist in relation to others. It is not only the person themself who is affected by death, but also the people who surround them in life. In addition to care staff, others can provide the reassurance that the dying person needs. The dying person themself can also give others peace of mind and the courage to live. This is the experience of many who have been with loved ones as they passed.

Human dignity is also theologically motivated by the conviction that we exist in relation to God in both life and death. Paul writes in Romans 8:38–39: "For I am convinced that neither death, nor

life, nor angels, nor rulers, nor things present, nor things to come, nor powers, nor height, nor depth, nor anything else in all creation will be able to separate us from the love of God in Christ Jesus our Lord." This is a foundation for hope in the midst of what is seemingly hopeless or limited, regardless of how death occurred. It applies to those who die peacefully, those who die in an accident where the body may not be found, those who take their own lives, those who are helped to die and those who fight to the end.

Thus, upholding the value of life is not the same as denying suffering and limitations, or that some people suffer more than others. Asserting that life is a gift is a way of affirming each person even when they are afflicted by suffering. The fact that a person is experiencing suffering does not in itself mean that they are of lesser value.

The principle of responsibility points out that it is our duty to take responsibility together for the life of every human being, even in the face of death. Vulnerability, limitation and loss are inevitable parts of life that need to be managed, not deviations from how life should be.

Those in favour of assisted dying see such a possibility as a way of taking responsibility for relieving human suffering. Assisted dying is then perceived as a means of shortening death, rather than shortening life. When death is inevitable, it should be possible to set a limit to suffering. Quality of life is preserved by abbreviating the dying process.

But there are other ways to mark this boundary that may be of

greater importance. A major obstacle to a dignified death in the care of seriously ill and dying patients is that other people withdraw from them. It can be both staff and relatives. A limit to suffering can also be set by ensuring that nobody is left involuntarily alone, that we take responsibility for each other even when the end is near. Even where there are experiences of suffering, hopelessness, anxiety and powerlessness, we can support each other by staying put. The church has the important task of being present through priests and deacons, as well as supporting staff caring for the dying.

A Christian view of human beings also includes emphasising that each person also contributes to the community with their weaknesses and vulnerabilities, not only with their strengths. It is the responsibility of every Christian to respond to people in such a way that they are strengthened in their sense of their own worth. In a performance-oriented society, this perspective tends to be rendered invisible. At the same time, suffering always exists and from a Christian perspective, it is crucial that we support each other, even in our weakness.

This is also the guiding principle of palliative care, which is aimed at those with diseases that cannot be cured. It aims to give people the opportunity to live a good life dependent on their circumstances.

Emphasising that life is a gift as the basis for applying the principle of responsibility also means that it is imperative to take suicide prevention initiatives. It is not only at the expected end

of life that we need to take responsibility for our fellow human beings. Every suicide is a tragedy. The aim is that nobody should have to live under such circumstances that they no longer consider life worth living. From the church's perspective, a change has taken place in that the view of life and suffering also encompasses knowledge of mental illness, a knowledge that was previously lacking. When the church condemned suicide, it was intended to discourage people from taking their lives. Today, we know that things do not work that way and that the principle of responsibility therefore means that we have an obligation to help people get through the darkness. Through the General Synod, the Church of Sweden has committed itself to gaining deeper knowledge of its opportunities to work to prevent suicide.

The principle of the best interests of the child in relation to the issue of assisted dying implies taking an explicitly child-oriented approach to the other principles. The human dignity of the child must be protected and responsibility must be taken for the child's death and dying in the same way as for adults. The principle of responsibility indicates the responsibility of adults to protect the child's vulnerability. The principle of justice also applies to children.

Involving and including children when a loved one is dying gives them access to the insights we have described. The human dignity of the dying person remains, and children can also affirm this, often just by their presence. We can take responsibility for each other in dying by also being there when life is coming to an

end. It is the responsibility of adults to ensure that children have good opportunities to be included. Adults need to make space for children's questions and concerns.

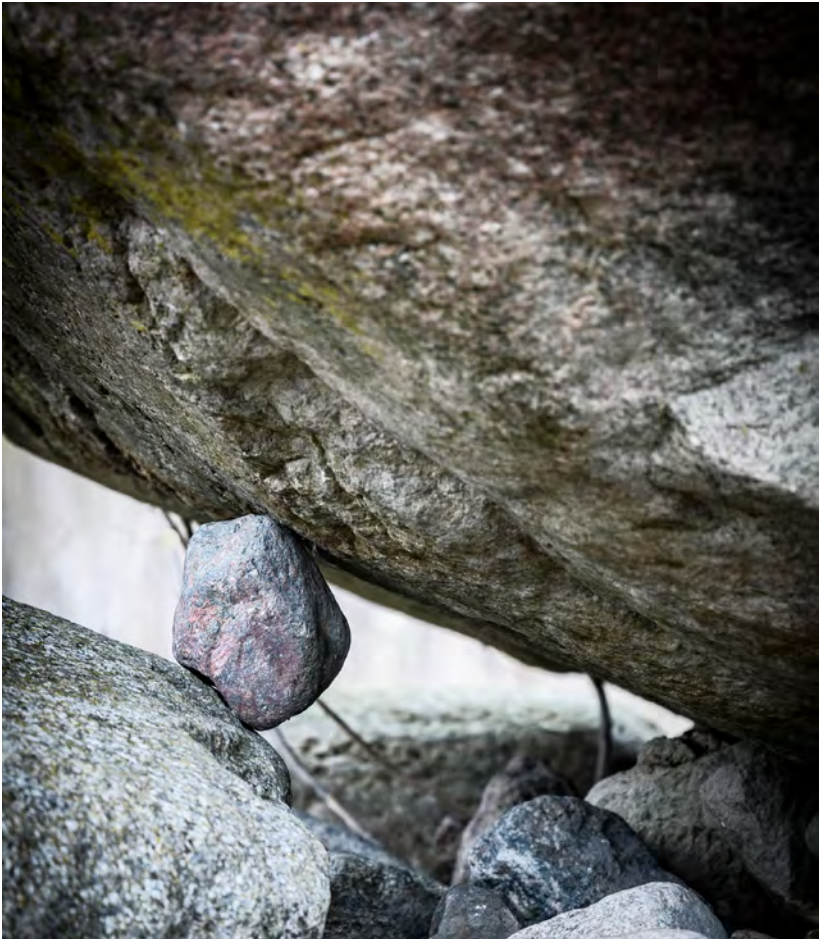
The principle of justice means that a society has a responsibility to ensure that everyone dies with dignity. For most people, this concerns the form that care at the end of life takes. Ensuring a palliative approach is therefore key.

Good palliative care is an essential part of a healthy and just society. We know that access to palliative care varies in scope and quality, which makes it imperative to work towards greater equality in this area. As we have seen, palliative care can help people find courage and meaning in life, even when time is running out for them. Receiving adequate symptom relief and being treated well in all four dimensions of suffering is crucial for everyone. People should not have to fear dying in pain – or dying alone. Each person should be able to rely on a community to look after them when they are at their weakest.

There is concern among groups living with severe illness or disability, and who can therefore be described as particularly vulnerable, that the introduction of legalised assisted dying in any form would change the view of death and, by extension, their status and value in society. There is an unspoken requirement not to give birth to children who have been shown by means of prenatal diagnosis to be at high risk of serious disease. This may eventually be followed by an equivalent unspoken requirement that the lives of those in the afore-mentioned groups should be shortened.

The view of how suffering should be addressed by society risks shifting towards an expanded notion of what makes life no longer worth living. As a result, instead of addressing the cause of suffering, we may extinguish the life that is perceived to be too painful.

Society has a structural responsibility and sets the framework for a person's autonomous choices. By ensuring that our human vulnerability is also taken into account, more people can be protected by structures and laws. How a society treats its most vulnerable is crucial to the security and trust of all. We are dependent on the knowledge that there is someone who sees and safeguards my human dignity even when I am at my weakest and afraid of being a burden. This is an existential cornerstone of a democratic society. On the issue of assisted dying, fundamental values are at stake. This can be addressed in different ways, but the question is central – because the answer to it affects the view of death and, above all, the view of life in the presence of death.



I Whether we live or die

Christian faith includes hope of eternal life. Jesus' resurrection is a victory over death and all that presents an obstacle to the fullness of life. Paul writes that "whether we live or whether we die, we are the Lord's" (Romans 14:8). Baptism unites us with Christ and gives us the hope of living, dying and rising with him. A human being's relationship with God extends from our first breath, throughout life, in death and beyond. The Christian confession that God never abandons any human being can bring comfort and peace in the face of life's greatest challenges and in the face of death.

Our belief that nothing can separate us from the love of Christ implies a conviction that also counts on life after death, but this does not mean that life on earth should be belittled. This life is precious, and it is God's will that we take responsibility for it. In this letter we have stressed that we all have an ability and a responsibility to reflect and make decisions on ethical issues. We have identified tools we have at our disposal and discussed their application. What now remains is to return to the fourth conceptual pair in a Christian view of human beings, **righteous and sinners**. This is a conceptual pair that we have said encompasses the other three: creator and co-creator; person and community; freedom and responsibility.

Sometimes we make mistakes, and there needs to be the possibility of reconsidering our position. Sometimes errors can simply not be changed. But the Bible's promise holds true: we belong to God and God will not abandon us. Sin does not set the boundaries to becoming righteous. It does not depend on us whether we attain to eternal life. Everything depends on God's love and grace.

The perception and experience of this life is coloured by belief in eternal life. It is therefore important that we do not just let life happen to us, but that we reflect on the questions of meaning and purpose. This helps us to face whatever happens and provides tools for when we have to make ethical decisions. We can draw new strength from the promise that "whether we live or whether we die, we are the Lord's".

II Tools to help with other issues

As we indicated in the introduction to this letter, our ability to find our way to informed ethical decisions is enhanced when we familiarise ourselves with the issues and expand our knowledge of the tools available for reflection. We have also emphasised that we are equipped with abilities and have been assigned responsibility to make decisions on ethical issues. We have given four examples of how ethical principles can be applied. They can also be applied to other issues.

We see this letter as a starting point – a common framework. The content can and should be developed and expanded upon in different contexts. But we provide tools in our letter with whose help we can address ethical issues of great importance in our time, based on Christian faith and tradition. They can be used for individual reflection and dialogue with others. They can serve as starting points for public discussions and for the church's contribution to public debate.

Finally, we recall the four dimensions of a Christian view of human beings and the four ethical principles that constitute a summary of the tools for orientation in ethical choices.

A Christian view of human beings

- Created and co-creator
- Person and community
- Freedom and responsibility
- Righteous and sinners

Ethical principles

- The principle of human dignity
  Respect the value and dignity of every human being.

- The principle of responsibility
  Take responsibility for your fellow human beings, especially when they are at their most vulnerable.

- The principle of the best interests of the child
  Let the best interests of the child be the guiding principle.

- The principle of justice
  Work to build a just society.

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Position papers in the Church of Sweden

The following is a list of the official statements of the Church of Sweden on the specific issues addressed in the bishops' letter. These are opinions from the General Synod's Doctrinal Commission and the Central Board of the Church of Sweden's responses to government inquiries. They all relate to specific issues and therefore do not provide a comprehensive picture. In addition some of these documents are also ecumenical.

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Abortion

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Assisted dying

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Opinion of the Doctrinal Commission 2001:11y on ethical issues and living wills
Opinion of the Doctrinal Commission 2001:14y on the Church of Sweden's position on assisted dying
Opinion of the Doctrinal Commission 2008:5y Active assisted dying

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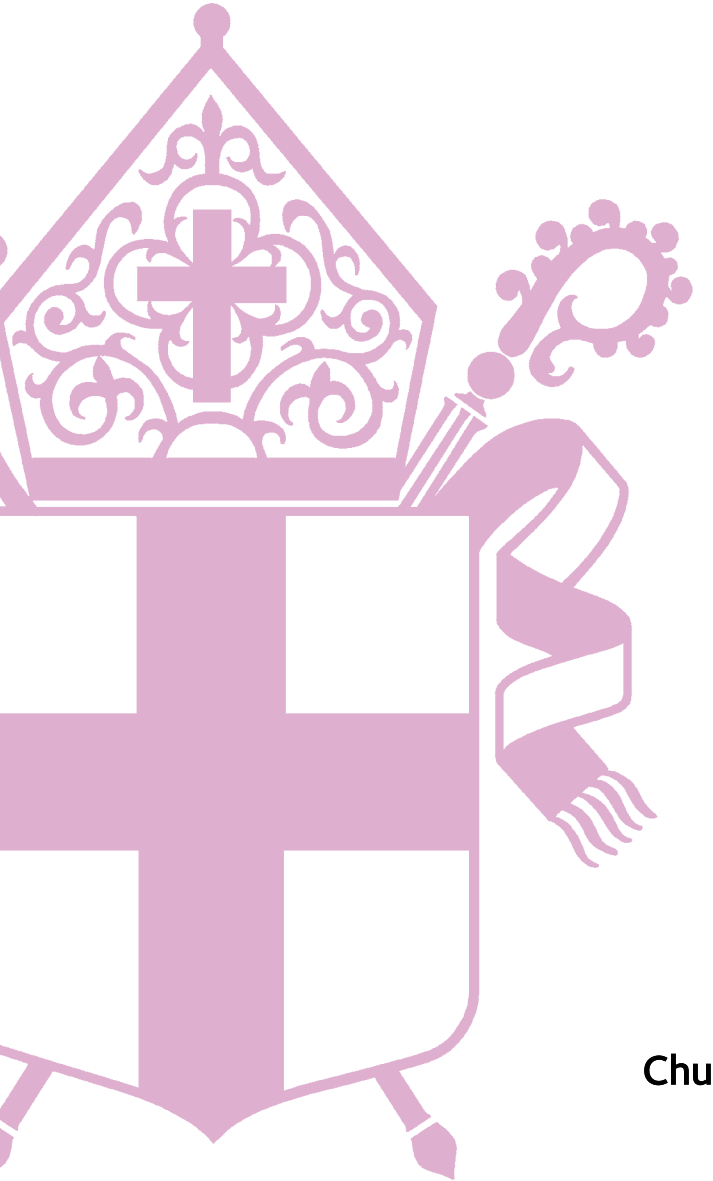

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