



Gemeinschaft Evangelischer Kirchen in Europa (GEKE)
Community of Protestant Churches in Europe (CPCE)
Communión d'Eglises Protestantes en Europe (CEPE)



A time to live, and a time to die

An aid to orientation of the CPCE Council
on death-hastening decisions
and caring for the dying

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**An Aid to Orientation of the CPCE
Council
on Death-hastening Decisions and Caring
for the Dying**

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Foreword

Many protestant churches have busied themselves in recent years with the ethical questions arising from the medical possibilities for life-extending measures. Particular attention is given here to the question of deciding for oneself on the end of life. The churches have published position papers which reveal various emphases and indeed differences. Mutually exclusive protestant positions on this question would not be a satisfactory contribution to the social debate.

In 2008 the Community of Protestant Churches in Europe therefore took up the question. A specialist working party under the leadership of the Expert Group on Ethics reviewed the individual position papers coming from the ecumenical context. These are documented in the publication by Stefanie Schardien (ed.), *Mit dem Leben am Ende*. The resulting aid to orientation was discussed and reworked in February 2011 at a consultation of the member churches with the participation of church leaders, university theology and experts from the fields of medicine, law and hospital pastoral care. After debating the different stages of the development of the text, the Council of CPCE now presents this result to the public as a protestant contribution to the discussion of a worthy dealing with the end of life.

The medical possibilities will increase further in the coming years and legislation in the individual European countries is changing. This aid to orientation, then, certainly does not deal conclusively with the questions that will arise. The debate will continue both on European and on national levels.

The results achieved so far can offer the basis for a joint protestant way on the European level. The aid to orientation is meant to encourage the churches to work further on addressing the problems in their respective contexts.

The Council of CPCE thanks all who have contributed to the emergence of this text, with special appreciation for the editorial work of Prof. Ulla Schmidt, Oslo.

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Executive Summary

Protestant churches in Europe recognize the challenges and questions that surround processes of serious illness, dying and death in contemporary European societies. Not only are there increasing numbers of people approaching death in health care institutions; their deaths are increasingly also a result of decisions arising out of medical treatment. This profoundly challenges how we understand death and dying and how we relate to people whose life is drawing towards its end. Confronted with these complex questions and dilemmas, Protestant churches in Europe search for constructive relations between fundamental elements and resources of their faith, and the context and conditions that surround these questions which relate to end of life.

Among the essential elements of Protestant formulations of Christian faith pertinent to this issue is the understanding of human life and its status. The basic qualification of a human being created in the image of God denotes a fundamental responsibility of a human being towards God, constituted by the life received from the hand of God. This responsibility towards God for the life received is on one hand exercised in freedom from being entirely defined by one's worldly conditions and innate qualities, and on the other hand, it is discharged in the midst of one's worldly positions and relation, as a freedom to lovingly serve one's neighbour.

A further essential characteristic of human life contained in the notion of image of God, is the fundamental dignity of human life. Protestant formulations of Christian faith find human

dignity grounded ultimately in human life's relation to God. It is the essentially relational character of human life, ultimately constituted through God's loving acts of creation and justification of human being that endows it with absolute and unabridged dignity. Human dignity is therefore connected to the many ways in which we receive our life daily through and depend on conditions outside human control, and not in any innate capacities or qualities.

The fundamental dignity of human life does not rest in its functionality, utility or independence. It is not affected by lack of productivity, nor diminished by the sense that there is no longer any pleasure to be gained from it. For example, a life affected by serious illness or disorder, is – perhaps for its entire life-span – completely dependent upon the care and assistance of others and does not conflict with or detract from human life's basic dignity, nor does it represent an inauthentic or undignified form of human life.

From this commitment to human life's unabridged and absolute dignity grounded in a relation constituted by God's loving actions of creation and justification flow several insights concerning responsibility for human life. Firstly it follows that human life is fundamentally entitled to protection against harm, violation and destruction, as it is also laid down in the fifth commandment against killing. But there also follows a basic responsibility to care for the neighbour, something we also find modelled in the life of the Lord. This comprises attentiveness and a compassionate disposition towards our neighbour, as well as concrete action of help and assistance, especially to the most vulnerable: the poor, the widowed, the disenfranchised and deprived, in short, those who are all too easily left at the margins of society and human community.

In this context we are especially reminded of the persistent and prominent element in Christian morality to care for the seriously ill and dying, also when there is no longer any hope of improvement or cure. The responsibility to care for the seriously ill and dying, for a life marked by pain, suffering and helplessness, does not flow from or depend on the chance of restoring it to a more healthy and well-functioning state, but from human life's basic dignity grounded in God's creative and justificatory relation to the human being. Important dimensions to this understanding of care we recognize in the notion and practice of palliative care as an increasingly natural component in national health care services. We want to emphasize and support any initiatives which prioritize and increase good palliative care facilities.

These basic commitments and concerns, which are derived from our understanding of the essentials of the Christian faith, can be brought into dialogue with the challenging questions which confront us when we have to face decisions towards the end of life.

Discontinuing or withholding life-prolonging treatment

Discontinuing or withholding life-prolonging treatment under given circumstances is not only permitted, but might in fact be required as an element of proper care and compassion for a seriously, irrevocably or terminally ill patient. It is important to ask if continued treatment does the patient any good; that is, curatively, palliatively, or in terms of sustaining a life that has quality in the Christian sense of being able to receive, sense and somehow respond to a love given. A consistent Christian tradition emphasises the duty to care for the seriously ill and

dying, also when there is no longer hope of cure or improvement, and thereby yields a strong presumption in favour of maintaining measures of care that can alleviate pain, discomfort and distress in life's final hours. On one hand, medical, clinical and nursing measures of care, whether life-prolonging or not, are vital moral responsibilities that have a very strong claim on us and can not easily be set aside in favour of other concerns. On the other hand, they are not absolute requirements beyond consideration of their implication for the patient and his or her situations. Although recognising the complex moral dilemma and assessment and the heavy moral concerns involved, Protestant churches are not prepared to reject, as always and absolutely wrong, (for example) the discontinuation of nutrition to patients in persistent vegetative states.

Moral concerns and evaluations not only apply to the decisions, but also to the process through which a decision is reached. The patient's well-informed and explicit wish against further treatment should be respected, and when a patient now not 'of sound mind' has previously issued an advance directive concerning treatment, this carries considerable weight, especially when there are no reasons to believe that it no longer represents the patient's will. In cases where there is no advance directive and the patient is irrevocably 'of unsound mind', communicative and consultative processes to reach a decision become particularly essential. They should be inclusive, involving a sufficiently broad spectrum of professions, health care personnel and counsellors. Close family-members, relatives and friends who know the patient well and can reasonably be expected to have the patient's best interest at heart should be thoroughly consulted and given sufficient time and space to come to terms with the decision, as well as with

the prospective loss of their loved one. They should not, however, be burdened with the final decision.

Palliative care, treatment and sedation

Protestant churches welcome the great advances in palliative medicine and care, within medical training, research and clinical practice. These developments have not only highly improved the possibilities for effective treatment and alleviation of physical pain and discomfort, it has also brought a wider array of dimensions of disease and approaching death into the perspective of care towards the end of life, including psychosocial and spiritual aspects. Not only has this heightened the quality of life for patients in life's last stages. It also proves to be life-prolonging rather than life-shortening, which much of the earlier discussions of pain-alleviation focussed on. This includes the rare procedure of palliative sedation, medically reducing a patient's level of consciousness in order to avoid the sensation and experience of otherwise intractable pain and suffering.

Although aware that palliative medicine and care will not solve all problems that occur in a medical context concerning the end of life, churches consider palliative care and the vast improvements in this field to be reflective of the absolute dignity that pertains unabridged to the seriously ill and dying life.

Euthanasia and assisted suicide

The European Protestant churches are deeply concerned about patients and relatives who go through an excruciating process of serious and terminal illness, and are awaiting death. Not only

might our societies still be inadequately equipped to assist in these situations, but as communities of faith we ourselves might also still not offer the companionship, support, comfort and hope that is the calling of Christian faith. Confronted with this reality there is reason to be mindful of these shortcomings over against patients and families, before too quickly passing any moral judgement. The basic responsibility of societies, communities and churches, is to ensure that adequate care, comfort and alleviation of pain and suffering are available and provided, and to promote communities and values that allow persons who are seriously ill and dying to perceive their life as the bearer of an inviolable and unabridged dignity.

Protestant churches find euthanasia ethically deeply problematic as a response to this situation, and for a variety of reasons. It conflicts with some of the most deep-seated moral convictions, not only of a specific Christian tradition, but of a wider common moral legacy, namely the ideal not to take innocent life and the duty to protect life, especially the vulnerable and frail. The arguments typically offered to rebut this basic moral conviction, namely autonomy and beneficence, do not carry weight as an ethical justification for euthanasia. Euthanasia is hard to reconcile with one of the most vital and persistent beliefs and commitments of the Christian tradition, namely that the fundamental and inalienable dignity of human life rests not in its capacity for independent self-determination and agency, but in the creating and justifying love that human beings receive from God in Christ.

This cannot be viewed purely as a matter of individual conscience which the state ought not to block by legal prohibition. Legalization would imply a kind of normalization and approval of euthanasia, turning it into an ordinary and

established element of medical and clinical practice. The fact that moral tragedies might occur, situations in which there is no way of avoiding deeply distorting an essential and vital moral good, could be given a legal loophole – as it has been done in some countries – by not prosecuting in rare and extreme cases, rather than by legalizing.

The member churches of the CPCE see it as their task to advocate a culture of solidarity with the dying and to criticize the tendency towards the individualization of suffering and the lack of human solidarity underlying the present discussion on euthanasia. The greatest social problem is not the excessive medical support but the loneliness of the dying.

The member churches of the CPCE support the protection of the human rights of the dying and the terminally ill. This includes both the right to life to the end, and also the right to decide against further treatment. Care and self-determination against treatment are not opposites. The CPCE member churches likewise criticize tendencies to water down the duty of care for the dying and terminally ill with an abstract reference to the principle of autonomy, without seeing the special need of the seriously ill and dying for special help and protection. Not only from a theological perspective but also philosophically, it is highly problematic to bind human dignity to an abstract principle of autonomy which confuses individuality with complete independence, and conversely sees any form of dependence, need for help and reliance on others, as a narcissistic insult. Such an understanding of autonomy leads to regarding suffering and weakness as unworthy of a human being and accepting only an abstract self-determined dying as commensurate with human dignity. Against this, in the light of the gospel, it is to be argued that human dignity consists in the

fact that God is powerful in the weak and that human beings are as much marked out by a capacity to suffer as they are by a capacity to love.

Even though euthanasia or suicide and assisted suicide cannot be justified ethically according to the view of the member churches of CPCE, they do realize the widespread public demand for legal decriminalization of active euthanasia.

The member churches of the CPCE argue for a shaping of social conditions but also of medicine and care in hospitals and care homes which respect human dignity in both living and dying. They support the hospice movement and further concepts of palliative care, which also include the dimension of pastoral and spiritual care. The member churches of CPCE therefore see their task as writing, creating and composing Christian forms of support in dying, including church rituals, with life, and developing them further in such a way that they protect men and women from speechlessness in the last phase of their lives, and provide aid and orientation in dealing with the finitude of life.

Caring for people and offering spiritual comfort is an essential part of 'being church'. This includes a clear task of the churches in civil society. They are called to voice protest when legal barriers which protect life are torn down. They are called to publically advocate adequate economic resources in hospitals and hospices to give those struggling with death the best possible care. They have the task to plea for creating an environment in society which fosters a fulfilled life for every member of society including those near to death.

1 Introduction: Protestant Churches on Euthanasia and Other End-of-Life Decisions

Dying is a part of life. But the circumstances of dying have significantly changed in recent decades. It is no longer the rule that people end their lives in the community of their family, their friends and neighbours. Today many people die in specialised care homes or hospitals. Such caring facilities provide medical care which was unknown in earlier centuries. But the changing social framework and on-going medical progress raise new questions. People wonder whether the intense use of all medical possibilities really means an improvement in the quality of their life or just the prolongation of a painful and long dying process. It challenges medical staff and family members of the dying to take difficult decisions on the application of medical treatments. It also urges politicians and societies to decide on issues regarding the quality of care, e.g. whether everything that is medically possible is to be financed by the community in the future.

In recent years many Protestant churches have published statements on end-of-life decisions. They offer considerations and reflections on the difficult and challenging situations and dilemmas currently facing all those who have to make decisions and choices pertaining to the end of life. Although based on many shared values and convictions, the churches have come to different responses on a number of specific questions; these

were also due to the respective social and legal contexts. At the same time all churches have stressed their responsibility for the best care of the dying and for support of all those who are facing the challenges of death.

In a consultative process the Community of Protestant Churches in Europe (CPCE) through its Expert Group on Ethical Questions has evaluated these statements and discussed the questions they raise. In this document it is presenting a common voice of the Protestant churches in Europe. First, it seeks to be mindful of the valuable and comprehensive reflective work done in many of our member churches on these complex issues. Second, it tries to accommodate and compile at least some of the important concerns and deliberations found there, as well as augment and supplement them where that is considered useful. And third, with the ambition and hope of offering resources for further reflection, it invites member churches – as well as other churches – to engage in further dialogue, exchange and discussion on these complex issues. We believe the churches have a twofold task and mandate in this connection, a public as well as a pastoral or congregational. They must engage with and participate in on-going public debates on legislation and policy-making. But they must also provide accompaniment for its members who are confronted with these difficult questions: those who are facing death, family members and friends to people who are approaching life's end, health care professionals, politicians and legislators, and parishioners who are coming to terms with the fact of their future death. Doing this, the churches not only have at their disposal rich resources for moral reflection, nurtured by Christian life and thinking. They are also trained in providing pastoral care and spiritual guidance for those who are struggling, guidance that are also shaped by a liturgical and ritual language which encompass the

width of human experience, of joy as well as of suffering and anxiety. Not at least, churches live by a promise that enables them to speak about a hope that stretches beyond our current, temporal life.

In this text we want to explore some of the resources of the Protestant tradition of Christian faith and life for reflection on some of these questions and dilemmas that confront us at the end of life, in medical and clinical contexts: such as, withholding and withdrawing life-sustaining treatment, analgesic treatment and palliative care, euthanasia and assisted suicide. The related but more specific issues of neonatal care and suicide will not be discussed *per se*.

2 Framing the issue I: Death and dying in contemporary societal, clinical and legal contexts

Euthanasia and other end-of-life questions, and more generally how we perceive and relate to dying and death, partly arise within a wider context and setting, consisting not only of medical and clinical dimensions, but also socio-economic, cultural and legal dimensions.

2.1 The socio-economic and cultural dimension

The questions of euthanasia and other end-of-life dilemmas are partly shaped by their socio-economic and cultural context and setting. Among the prevalent and relevant features is the fact that processes of dying and death today occur, to a large extent, within the institutional and technological medical settings of hospitals, nursing homes and other care facilities and units. Until the early 19th century, dying and death predominantly took place in the immediate context of home, family, neighbours and community. Various factors together, however, have changed all this. Socio-economic factors have changed the family and the close community as the setting for dying and death. Not only the fact that employment is predominantly found outside the home and immediate community, but also the demand for a flexible labour force, increased mobility, changing patterns of family life and communication between

generations, are only some of the factors that have changed the conditions of the primary family as the context of housing and sustaining processes of dying and death. Urbanisation not only heightens mobility and changes patterns of life-long, stable abodes, but also affects conditions for small, tight and stable communities as locations of caring and nurturing. In short, changing social structures in industrial and post-industrial societies have contributed to the transferring of processes of dying and death from the close setting of family to an institutionalised setting of health-care facilities.

There is no reason to deplore this development. Health-care facilities in general have at their disposal medical expertise, technological equipment and effective means for palliative treatment, and not least health care personnel are trained and experienced in caring for the terminally ill in ways that meet with important ethical standards of professional ethics. In general these facilities also provide the seriously and terminally ill with better security of proper care, for example in situations where families and close ones are not willing or not able to care properly for an ailing family member, or for people who lack close family relations. That said, the kind of comfort, support and companionship that family members and close relations might provide for a dying patient should be, and normally are, recognised as important resources, and not a disruptive element to professional health care. Under favourable circumstances this might allow the patient who desires it to die at home in his or her own surroundings, accompanied by loved ones.

Demographic changes, such as raised average life expectancy and a growing proportion of older people in the population put hospitalised and institutionalised dying under severe strain in many European countries. Furthermore, more resources are

used for medical treatment and care in the very last weeks of life than for medical treatment, and running costs for palliative-care units are higher than for other hospitals. In several countries this situation leads to increasing political pressure to cut or limit economic costs for treatment and palliative care at the end of life. Nursing homes and palliative care units are facing budget cuts, requirements of effective management and rationalisation, with reduction of their activities as a result. This is sometimes accompanied by suggestions from politicians to the effect that dying patients can equally well, if not better, be given companionship and support at home in their familiar setting. Against this, it must be remembered that even though family and close ones in many cases provide invaluable comfort and support, many of the social bonds and structures that once underpinned family as the immediate context of care at the end of life have long since been eroded. Family and tight communities cannot compensate for the lack of resources invested in palliative care and medical and nursing facilities designed to offer appropriate care for the terminally ill.

In addition to these more material, socio-economic conditions it is sometimes suggested that the changing and increasingly permissive attitudes in the European populations regarding euthanasia and end-of-life questions also reflect more comprehensive cultural patterns and values. With concepts suggested by philosopher Charles Taylor as characteristic of dominant value patterns in contemporary (Western) societies, one might say that relations to, and decisions concerning, the end of life appear to be increasingly governed by expressiveness and authenticity. Expressing one's inner true self, acting authentically in accordance with one's preferences and commitments, takes precedence over acting in accordance with an external, objectively given moral order. For some this

might entail avoiding situations with a loss of self-control or being left completely helpless, entirely dependent on others and without prospects of enjoying those things that used to make life worthwhile and dignified. For others, it might entail seeking a purpose in life along with coping strategies even in situations of dependence and pain at the end of life. Either way this shows how the question of euthanasia is also embedded in value patterns that affect how euthanasia, assisted suicide and other end-of-life questions are interpreted and described. Assessing these moral dilemmas is not simply a matter of passing moral judgement and evaluation, but also about offering interpretive resources that allow interpretation of loss of control and productivity and are marked by complete dependence as a dignified human life.

2.2 A Clinical context

Obviously socio-economic factors alone have not led to the transferring of dying and death from the intimate setting of home and family to the institutional and professional setting of hospitals and nursing homes, but also the huge advances in medical sciences. As a result of developments in medicine and health care, it has become possible to keep patients alive much longer with diseases or injuries that would previously have ended their lives at a much earlier point. Medicine and medical expertise have come to play a much larger role in supporting patients at the end of life. Not only does this development compel us to reconsider and reflect upon our understanding of and attitude towards death as a given, human condition, as well as how we relate to people who are approaching the end of life. It also implies that death, to a larger extent, occurs as the result of an explicit medical and clinical decision regarding treatment and proper health care, for example whether to withdraw or

withhold treatment, or to intensify analgesic treatment. Unlike the traditional saying, stating that we can only know *that* we shall die, but not when nor how, the *when* has now – within limits – increasingly become subject to decision and influence.

This obviously confronts health-care personnel, patients, their families and counsellors in the concrete clinical practice with a number of difficult dilemmas about how to make responsible decisions, for example, when and under what conditions to abstain from further medical treatment. These questions have increasingly been located within a wider frame concerning how to care properly for patients who are approaching death, and not only how to prolong their lives. It is increasingly implied that caring properly for a person who is dying might not only involve attempts to prolong life as much as possible, but also decisions as to when it is justified to abstain from treatment. Growing research and increased competence regarding the practice and priority of care for the dying have also emphasised its interdisciplinary character. Proper care is not only directed to medical treatment and curative attempts, but must attend to a wider range of the patient's physical and bodily needs, such as good management of pain, and also psychological needs, social and relational matters, as well as spiritual issues and needs. In short, there is a growing awareness that end-of-life situations increasingly taking place in medical and clinical settings require not only curative efforts but also caring activities. So, in certain circumstances, attempts to cure ought to be discontinued in favour of care, and that care needs to address a wide array of dimensions of human life, not only its physical nature.

2.3 Legal and political aspects

As dying and death increasingly take place in the context of health-care institutions, they also increasingly become the topic of legislation and political governance. However, how clinical actions/practices are regulated and on what level, differs a great deal among European countries.

In 2002 the Netherlands passed the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. According to this law, prosecution of a doctor who has performed an act of euthanasia or assisted in suicide can be suspended provided a review board establishes that the act meets with certain conditions, including that the patient is suffering unbearably and irrevocably, and that there is a persistent and voluntary request for euthanasia. Unless these conditions are met, euthanasia as well as assisted suicide is a criminal offence. The penalties have even been increased.

The Belgian Act on Euthanasia passed in May 2002, states that the physician who performs euthanasia commits no criminal offence provided certain conditions are met, conditions that are less strict than in The Netherlands.¹ A more or less similar law

¹ The patient must be legally competent and conscious at the moment of the request, not a minor, and must have forwarded a voluntary, well-considered and repeated request which is not the result of external pressure, in a condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from serious and incurable disorder caused by illness or accident. The physician should consult with a second colleague, and a National / Federal Control and

was passed in Luxembourg in March 2009, likewise stating that doctors performing euthanasia or assisting in suicide should not be prosecuted, provided certain conditions (similar to those mentioned in the Belgian law) are met.

In Switzerland, killing on request is forbidden, but assisting someone in committing suicide is a criminal offence only if it is done for selfish reasons. This is taken to imply that if it can be established that this assistance was motivated by good intentions of bringing about a requested death for the purposes of relieving suffering and not for selfish interests, it is not a criminal offence and should not be prosecuted. Under this provision organizations like EXIT and DIGNITAS legally provide help in suicide in Switzerland. The Swiss Academy of Medical Science still in principle rejects the involvement of doctors in the suicide of seriously ill people, but concedes that there are individual cases where there is a conflict in which doctors can arrive at a different decision.

In Germany suicide through the assistance of someone else is also not a criminal offence, but certain conditions apply regarding the absence of manipulation, and that a duty to rescue persons in emergency has not been neglected.

In other European countries euthanasia and assisted suicide are prohibited (such as the UK, Norway), or legislation is silent or indirectly prohibits it through other legislative institutions. In

Evaluation Commission is set up to evaluate whether the cases reported by doctors meet with these conditions of not prosecuting.

several countries, there is considerable public and political debate, to a certain extent stirred by high-profile cases in the public media. In the UK the case of Diane Pretty stirred considerable debate, even going all the way to the European Court of Human Rights, and quite recently the case of Debbie Purdy has been suggested as a reason for introducing a change in the legal situation in the UK, providing an opening for assisted suicide. However, the recent case of Debbie Purdy is seen by some to turn this situation around. Earlier this year the House of Lords (the highest court in the UK) ruled that it was in fact a violation of human rights that the country's public prosecutor could not spell out to Debbie Purdy (a progressive MS-patient) and her husband the criteria under which the husband would be prosecuted for assisting in her suicide, and therefore could not say whether or not he would in fact face prosecution. The House of Lords ordered that the criteria under which anyone will be prosecuted for having assisted in someone else's suicide must be spelled out. In France a few years ago the case of Vincent Humbert received wide attention, and eventually led to legislation concerning abstention or withdrawal of life-supporting treatment. In Italy Eluana Englaro, a patient who had been for years in a persistent vegetative state, was transferred to another medical facility which, unlike the one she was originally committed to, at her father's request, discontinued her tube-feeding, and this led to her death within a few days. This situation caused a heated debate, whether this kind of discontinuing life-sustaining care could ever be acceptable.

Other countries see less political pressure in the direction of legalising euthanasia (e.g. Germany, Denmark, Norway), but might still have considerable debate and legislative work regarding other kinds of end-of-life decisions, such as

legislation regulating the status of advance directives, or developing guidelines for life-prolonging treatment on seriously ill and dying patients (Germany, Austria, Norway).

However, in other European regions the situation is completely different, legally as well as mentally. In Romania, for example, there is no legislation concerning euthanasia and assisted suicide and neither is the much debate on these issues, mainly for cultural and religious reasons. No legal initiatives exist at the moment, nor has the medical council and association instigated debate. This does obviously not imply that care for the dying and the questions that arise in this area is not an issue. In the context of hospices the problem of assisted death is encountered and confronted in a provisional way at a concrete and regional level. The impulses that flow from this context, however, stir little interest, probably because the main understanding is that dying takes place at home, in the setting of the family. Culture and religion appears to play a large role, as death is primarily considered in a social perspective and as a social phenomenon, rather than an individual and institutional. Dying is a family matter, and derivatively a matter for society and for the church. In this sense, the Romanian situation is quite different from a Western-European discourse.

In the Czech Republic euthanasia is not mentioned in the law. Admittedly, the bill of 2004 did include a short paragraph on it, with the intention was to say that it is a crime, but the final version of the law (Nr. 40/2009) does not contain this item, which implies that euthanasia is legally considered murder. A proposal for legalisation of euthanasia was shortly discussed in the Czech Parliament in 2008. This was an initiative from a small number of MPs, but was not even approved to be discussed in the plenary in the parliament. Public opinion polls

show that the majority of the population (55-60 per cent) lean towards tolerating euthanasia, whereas a minority of 25-30 per cent is strongly against it. The medical doctors are almost unanimously against it. Euthanasia is not a big issue in the public. In the public euthanasia is not a big issue, only when casual initiatives of interest groups occur – for or against it.

In sum, we face a highly varied situation throughout Europe. In several parts of Europe, as well as on the level of the European institutions, dilemmas concerning end-of-life decisions in medical and clinical practice cause considerable political and legal debate. In other parts, especially the central and eastern Europe, there is scarce legislation, little public debate and little pressure to legislate in these matters, to a larger extent considered as matters of the family and the community, rather than the individual and the public institutions.

The issue is also on the agenda at a pan-European level. In 1999 the Parliamentary Assembly of the Council of Europe passed a recommendation on the protection of the human rights and dignity of the terminally ill and dying.² At the centre of this document is the question of how far the right to self-determination, which also applies in the last phase of life, extends, and how far it is limited by the right to life, which includes the prohibition of any deliberate killing (Art. 2 European Convention for the Protection of Human Rights). An initiative within the Council of Europe has sought to revoke this 1999 recommendation and replace it with a document, which,

² Protection of the human rights and dignity of the terminally ill and the dying (Recommendation 1418 [1999]).

while emphasizing the need for improved palliative medicine, also argues for the right to euthanasia and medically assisted suicide.³ However, in 2003, the Committee of the Council of Europe on Legal Affairs and Human Rights sharply rejected this proposal by the Social, Health and Family Affairs Committee and its president Dick Marty, and reaffirmed the 1999 recommendation of the Council of Europe.⁴

2.4 Euthanasia in the historical context of the German National socialist regime

The National socialist regime in Germany introduced so-called “euthanasia-programmes” under which mentally ill and disabled people were systematically killed. In the current debate on euthanasia these programmes are sometimes used to warn against euthanasia as a threat to the unique and equal dignity of all human lives. It is vital not to forget past wrongs of medical and legal institutions; recollecting them might make even more clearly the vital and indispensable values and concerns that contemporary society’s institutions and practices must uphold. However, the German National socialist euthanasia programmes should not be confused with what is today

³ Euthanasia (Document 9898 of the Parliamentary Assembly of the Council of Europe), 10.9.2003.

⁴ Document 9923 of the Parliamentary Assembly of the Council of Europe, 23.9.2003.

discussed under the heading of euthanasia. They were state-organised, systematic killings of people without or against their will, based on the authorities' evaluation of some lives as not worth living, or detrimental to society's genetic pool. Today's discussion typically concerns lawfully ending a person's life at his or her voluntary and explicit request, based on this person's own evaluation of life as unbearable due to illness and pain.

3 Framing the issue II: Ecumenically

A Protestant discussion of euthanasia must also take into account how members of the Conference of European Churches (CEC) and the Council of the European Conferences of Bishops (CCEE) have also committed themselves to work together on ethical questions, including end-of-life decisions. Christian churches face the task of finding the narrow path between common Christian answers which shape society and the denominational imprint of their ethical position in the discussion about the end of life. Churches (e.g. the Protestant Church in Germany, the German (Roman-catholic) Bishops' Conference, and the Ecumenical Council in Austria) demonstrate ecumenical unity without disguising their distinctive character.

Positions taken by the Roman Catholic Church in dealing with the end of life stand out by virtue of the homogeneity of their argumentation. At the centre is always an understanding of euthanasia as killing, which is absolutely forbidden as an act against nature and against God's law. Forms of passive and indirect euthanasia are distinguished from this by being explained as exceptions. So despite its fundamental agreement with the demands of the Protestant churches, the official Catholic position differs clearly in tenor: an optimistic view of human beings is presupposed. According to this, believers can orientate themselves to the divine will by means of their reason and consequently cannot want euthanasia. Moreover, from the Roman Catholic perspective, a potential meaning can be attached to undergoing suffering, since it is bound up with the suffering of Christ in a special way. From an ecumenical

perspective, with this attitude the Catholic position clearly comes close to the Orthodox position and to Independent Church positions in its unequivocal and final judgment. Only in recent times have both Orthodox and Independent Churches taken part more intensively in the discussion about euthanasia. In the past the more marked separation of the life of faith and social questions had led these churches to be very restrained in making public statements.

By contrast, Protestant Churches can and should introduce a special voice into the ecumenical discussion. Although a plurality of ethical judgments is neither alien to Protestant faith nor a danger to it, it hardly seems wrong to point to basic features which have crystallized in the large number of Protestant statements, declarations and individual positions, which deal with conflicts at the end of life.

4 Theological and ethical framework

This document affirms as its basic theological and ethical framework what has previously been agreed among the CPCE member churches and expressed in documents such as “Protestant Texts on Ethical Decision-Making” (Leuenberg Church Fellowship 1997), and “Law and Gospel” (Community of Protestant Churches in Europe 2007).

4.1 Human life: created in the image of God

Fundamental to a Christian, Protestant, view of human life is the idea that human beings are fundamentally defined through their relation to God. Being created, justified and renewed through God’s loving action is what ultimately describes what it is to be human. As a consequence the human being’s ultimate status as marked by an intrinsic and absolute dignity is also grounded in something beyond human life itself, namely in its relation to an outward reality. This is also captured in the basic description of humanity being created in the image of God, with a new life united with the resurrected Christ as its ultimate goal, all of which is grounded in God’s loving actions upon humankind and creation.

This first of all implies that life is given by God, rather than acquired through an act of human power and control. Sometimes the expression of life as a gift is used to account for this dimension. This metaphor captures how life is bestowed, without consideration of merit or deserving, to be received with gratitude. But unlike other associations evoked by this concept, life does not become a human owner’s property to be freely

disposed of. Instead it becomes the responsibility of human beings to be guarded with respect, love and care. However, one would be very mistaken to interpret human life's status as the image of God as a moral task. Quite on the contrary, it is vital to a protestant tradition that being the image of God is grounded in God's creation, and is therefore solely the gift of God. The doctrine of justification by faith further underlines that human being's status as justified in relation to God, is a status that God gives out of His love and grounded in the death and resurrection of Christ. It is not something that ensues from human responsibility or from human moral accomplishment. This is also true of the moral questions addressed in this text. It is not by successful or failed moral discourse and practice that Christian believers establish or maintain their status as God's image and justified to God, but solely by receiving the gifts of life and forgiveness of God's love.

Being created in the image of God testifies to the unique status and dignity of human life, reflected in biblical texts such as Psalm 8. This dignity does not derive from the value that we are able to find in it or derive from it. It exceeds the conditional and contingent value deriving from human power and preferences.

The teachings of the Reformation famously articulate how God's creation of human life occurs in and through the many concrete ways that life is upheld and nourished. Nature is life's basic origin and constant source of renewal; close relations to other human beings are an essential ingredient to life's continuous thriving and survival; being set into a culture and society equipped with language, cooperative patterns and institutions, provides the necessary means not only for living in a community with others, but also for self-reflection and self-articulation. This testifies to the basic dependence of human

life. Being dependent on factors external to the control and management of the human subject is an inescapable and essential dimension of human life. There is no conflict or contradiction between the dignity of human life, and human life's fundamental dependence. Indeed, there is an intrinsic and intimate connection between the two in the sense that life's basic dignity is inescapably linked to its dependence, to its not being the self-acquired product of human being's own forces.

This also underlines the basic relational character of human life. That human life is lived and thrives through relations is not just a contingent fact about our lives. It inheres in the very constitution of human life, grounded in the relation to God. This fundamental relation is reflected in the web of relations of the concrete human individual, most fundamentally perhaps with biological parents, but then with a multitude of different relations with family, relatives, with friends and colleagues, with people in one's local community etc. These many relations, whose concrete shape will vary immensely from individual to individual, are essential to life as we receive it, sources of joy and gratitude, but also of loss and frustration. It is essential to recall and explore this fundamental role of relationality to human life also when addressing end-of-life issues.

4.2 Moral responsibility: responding to God's loving actions of creation and redemption

Human moral responsibility is grounded in God's loving action upon the world and human life in creation and redemption. Human being's most fundamental relation to God is one of receiving God's gifts in creation and justification, not one of

moral responsibility. But responsibility follows from receiving these gifts, as a responsibility towards God. Fundamentally, human beings are defined by their relation to God, and not by their relation to worldly authorities or institutions, and it is ultimately to God that human beings answer. This responsibility towards God, however, is properly executed and discharged by undertaking responsibility for worldly affairs, for example within society's institutions, professions and authorities. God's creative and redemptive action in the world as the vantage point of moral responsibility implies that value and goodness ultimately originate in God's love, not in human power or will. Value does not flow from the human activity of valuing. The doctrine of justification by faith reminds believers how attainment of the ultimate goal and good for human life and the constitution of a loving relation to God, the transcendent ground of our lives, is not to be found in ethical and moral successes and failures. God's gift of forgiveness unburdens human life of the requirement to redeem itself through moral works and deeds and sets it free: free from the burden of serving one's own ultimate ends, and free to serve the neighbour's worldly good in loving responsibility. That the human being is basically free is therefore not equivalent to self-determination, but inherently connected to the responsibility for one's life and for one's life in relation to others. Thus Protestant understanding underlines the inextricable bond forming the triad of responsibility, freedom and love.

Reflecting on how this responsibility is discharged, Protestant tradition draws on various sources of moral insight and various moral capacities. Although these are sometimes articulated as alternatives, they are maintained as complementary in "Protestant Texts on Ethical Decision-Making". On the one hand, the Protestant tradition acknowledges human practical

reason and its expressions in shared moral values and beliefs, as well as in collective practices of moral communication and deliberation, as an important source of genuine moral insight and basis for cooperation across contexts of faith, culture and tradition. Theologically this is often linked to the idea of God's twofold rule, that God also rules the world through the law by means of many kinds of human social, political and cultural practices that sustain and nurture a viable human community. On the other hand, Protestant tradition invites us to view reality and human existence in the light that falls from Christ's redemptive work and the promise inaugurated by the gospel, thereby refusing to make the autonomy or goodness of any worldly order created through human practice or moral effort absolute. Theologically this is grounded in the Lordship of Jesus Christ and its disruption of the power of evil, as proclaimed in the gospel (cf. Leuenberg Church Fellowship 1997: 25–37).

The fact that human beings are thus responsible in relation to God, and therefore must be recognised as free, implies encouraging their capacity and effort as to how best to discharge this responsibility, for their own lives and in relation to the lives of others. Also, regarding ethical and moral decisions, the human person basically answers to God, and must form his or her judgements in personal responsibility before God (cf. CPCE Law and Gospel: 285).

Within this basic framework, certain elements to the Christian tradition and narrative are particularly relevant and pertinent to understanding and interpreting the reality of the end of life, and

reflecting upon concrete questions and dilemmas that confront us within this realm.

4.3 Human life: entitled to protection

From respect for the dignity of every human being and from the fact that human beings are made in the image of God, there follows a basic duty to protect human life. Human life must be protected from destruction, infringement and violation in all its phases from conception to death. Violating and harming a human being is in grave conflict with the unique dignity that qualify human life. This duty to protect from destruction and harm not only concerns physical human life, but also concerns the human being as a person forming a biography. The duty to protect human life therefore involves protection of, and respect for, those aspects of human life and personhood that allow us to form a biographical history and exert our responsibility to others and to God, such as autonomy and self-determination.

As an obligation to care for human beings in their need and vulnerability it applies particularly at the limits of life. This is clearly coined in the traditional expression *in dubio pro vita* – in doubt, for life: this principle accords with Christian faith and practice, and is indebted to God’s commandment, “You shall not kill.” However, this basic duty to protect a person’s life does not, in and of itself, entail that person’s obligation to live at all costs, nor does it legitimise the coercion of patients to receive treatment or deprive them of their rights to resist further treatment. Recognising life as ultimately a gift also implies recognising and accepting the finitude of life, rather than trying to overcome and conquer its limitations and finite character.

4.4 Care and compassion for the sick and dying

The duty of care and the virtue of compassion towards other human beings, in particular towards those who are in need, have been essential to Christian life, and are key ingredients in Christian morality from the very start. Paul's letters contain several accounts of what a Christian life should be, and how it must give prominence to ideals such as care and compassion. Also, in the life of Jesus Christ, Christian believers find a model for a life that attends concretely in care and compassion to people in need, the poor, the ill, the widowed, those left at the margins of society and human community. His care targets directly the various dimensions of human life in need: its physical dimension by feeding the hungry and healing the sick, its relational dimension by inviting the excluded and marginalised into fellowship and community, and its spiritual dimension by offering comfort to those in despair.

This image of Christian life, modelled by Jesus Christ and described by Paul, underlines the responsibility of caring for seriously ill and dying persons. This has been a prominent part of Christian morality, and in contrast to its surrounding ancient Hellenistic traditions, Christianity has been committed to caring for the ill even when cure or alleviation is no longer possible. This is inspired by the high standing of every human being as loved by God, and by the model and ideal left by Jesus left to his followers - to care for and attend to the ill and vulnerable.

In line with this view comprehensive research, education and training programmes on care towards the end of life have over

the last years underlined its interdisciplinary character and its need to respond to all affected dimensions of human life.

Caring for the dying involves caring for the patient's physical and bodily needs, also when cure is no longer possible and there is no prospect of further medical treatment to improve the medical situation. This includes effective management of pain to keep the patient as free of physical pain and discomfort as possible, alleviating other physical symptoms that cause discomfort, such as severe nausea, suffocation, itchiness, bedsores etc. But equally important it involves attending to other dimensions of the patient's life that might cause distress during serious illness and towards the end of life: psychological suffering such as anguish, anxiety and depression, loss of sense and meaning, problems of maintaining relations and bonds with family, relatives and friends, as well as finding one's place in society; spiritual needs concerning the handling of life's ultimate trust and hopes. Churches are involved in all these dimensions of care and compassion. They often run diaconal health care facilities and palliative institutions, set up programmes for visiting seriously ill and elderly living at home, and provide pastoral services to those who are institutionalised at hospitals and nursing homes. Doing this, they not only attend to the physical and medical needs of the seriously ill and dying, but also offer pastoral and spiritual guidance and comfort. Through their rich liturgical and ritual language and practices, churches and ministers are able to offer accompaniment to the ill that address other needs than the physical and medical. Through the Christian community's prayers, biblical readings and hymns, the ill and dying might be able to express their experiences and emotions of pain, despair and meaninglessness, but also of confidence and faith, and thereby to find comfort and spiritual strength. Some might also find strength by being

included in the hope beyond death which grounded in the promise that carries the church and all believers.

A multidisciplinary and holistic approach to palliative care, which does not pertain to terminally ill patients only, is explicitly affirmed in WHO's definition: "Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual." (World Health Organisation 2007: 3). The definition continues by concretising the various aspects of palliative care, including among other things

- relief of pain and other distressing symptoms,
- affirming life and regarding dying as a normal process,
- neither hastening nor postponing death,
- integrating psychological and spiritual aspects of patient care,
- supporting patients to live as actively as possible until death,
- offering support to help families cope during patient's illness and their bereavement,
- using team approach to address needs of patients and their families,
- enhancing quality of life.

Palliative care in general, and caring properly for the dying in particular, thus involves a number of skills, competencies and disciplines.

These basic accounts of moral responsibility, the unique status and dignity of human life, and the duties and ideals of care and compassion towards those in need, provide an interpretive framework through which more specific end-of-life issues can be explored and discussed. Still, definitive and absolute solutions do not flow directly from this interpretive framework. Responses to specific issues are better developed through a dialogical process, where the concrete reality is brought into a mutual conversation with this interpretive framework.

4.5 Regard for the patient

It follows from this that the chief concern and focal point must be regard for the person who is going through serious illness, facing not only the stress of severe physical pain, but also having to deal with the psychological burdens as well as the existential and spiritual pain and affliction. Protestant tradition teaches us not to be concerned with our own moral perfection, successes or failures, but to be concerned with and direct our efforts and resources to the service of our neighbour, in the love commanded by the Lord. Thus abstract reflection and deliberation on moral rules, ideals and norms in relation to end of life issues can never be an end in itself, but is important only to the extent that it provides better understanding and critical probing of what it means in a concrete situation to serve the neighbour in responsible love. The inescapable framework and focus of our deliberative efforts must always be the regard for and service of our neighbour. This calling to loving regard for the neighbour implies attentiveness towards the neighbour,

recognition of the uniqueness of his or her biography, relations and self-understanding. Regard for the neighbour requires that one does not reduce him or her to illness, to remaining prospective life-expectancy, to physical condition or functionally, or to familial or social status. It is a core idea within our protestant legacy that the human individual cannot be reduced to his or her contingent condition, be it severe illness, anxiety, conflict-ridden relations or sense of loneliness and abandonment.

Regard for the other, therefore, always requires being attentive towards the unique character of that particular life. People come to terms – or fail to come to terms – with their physical suffering and imminent death in quite different ways. They involve close family and relations, or refrain from doing so or have to go through periods of serious illness unaccompanied by intimate and close relations. They deal with the vulnerability that is typically involved in severe disease and approaching life's final stages in diverse ways. The regard for the other that neighbourly love commands, must avoid generalising and standardised images of personal biographies, and what it is like to go through times of serious and terminal disease, struggling with physical, mental or spiritual anguish. It must pay attention to the concrete human individual. This implies paying attention to how this person's life is embedded in and influenced by relations or loss of relations, and how this dimension of life affects the possibility of coming to terms with one's illness and death. It implies taking seriously and giving expression to the many and conflicting emotions involved in such a state, such as despair, anxiety, loss, hope, sadness, anger and grief. Furthermore, it implies staying by and accompanying rather than abandoning the person, also when he or she makes choices or embarks on a course of life not necessarily approved or

condoned by the church. The calling of churches and of Christians to care and be compassionate for a person, is not conditional upon the moral acceptability of this persons' choices or character. This is particularly important when churches operate in contexts with overwhelming support of practices and legislation that does not conform to what churches typically consider as ideal and laudable practices. In such situations churches, congregations and Christian believers find themselves challenged to negotiate between their calling to be faithful to their understanding of a good, human life, and their calling to care and be compassionate for the concrete human individual who is led by a different vision of what a good human life can be. In circumstances like that, churches ought not to advocate and proclaim their visions of a responsible, moral life, at the cost of abandoning a person in suffering and despair.

5 Withholding/withdrawing life-prolonging treatment

5.1 Clinical context

In what situations is it right to withdraw or withhold life-prolonging treatment? This question frequently confronts severely ill or injured patients, their family members and health-care professionals. In hospitals and nursing homes it arises in relation to terminally ill patients, for example, those suffering from cancer or serious, neurological diseases, and in relation to patients of old age whose health condition is in general gravely reduced. It also arises in relation to patients who, for example, as a result of severe brain damage due to illness or trauma are permanently and irrevocably in a state of gravely reduced functionality (such as permanently comatose patients, or patients in a persistent vegetative state), who might nonetheless with treatment continue to live for months or even years.

Life-prolonging treatment can be defined as “any treatment and measure which postpone a patient’s death. Examples are heart-lung rescue, other forms of respiratory assistance, artificially administered nutrition and hydration (intravenous or through a PEG-tube), dialysis, antibiotics, chemotherapy”.⁵ It describes

⁵ This definition is taken from a draft for national guidelines for decisions regarding life-prolonging treatment in seriously ill and dying patients, recently issued by the Norwegian

treatment that sustains life but no longer has any curative function. Discontinuing or abstaining from life-prolonging treatment thus understood is in principle an accepted and necessary element in clinical medical practice, but is also saturated with difficult decisions and judgements in relation to specific patients. Among Christian churches and within Christian ethics it is likewise widely accepted that the duty to protect and respect human life does not entail a duty always to do whatever can be done to prolong life as long as medically possible. Still, this general opening for abstaining from life-prolonging treatment leaves unresolved the questions relating to the circumstances and conditions under which life-prolonging treatment should be continued or discontinued.

Typically these questions arise in situations where doubt occurs as to whether continued, life-prolonging medical treatment in any sense benefits the patient, or whether it is futile and burdensome. An attempt at distinguishing between various indications for foregoing further treatment on the grounds of potential futility and burden to the patient could look like this:

Directorate of Health (Helsedirektoratet 2008). How to define life-prolonging treatment is obviously a matter of discussion. As will be shown below some (in particular Catholic) positions will leave out nutrition and hydration from medical treatment, instead defining it as care that can under no circumstances be denied.

- Patients whose treatment prolongs a troublesome and painful dying-process, for example postponing death by hours, days or a few weeks, but where the patient will be in a state of pain and discomfort that cannot be alleviated, and where there is no prospect of expression of life from which the patient might benefit.
- Patients whose treatment prolongs a life in great affliction and pain, i.e. where treatment might lead to survival, but with the prospects of a life in which physical and/or mental consequences will be severely harmful to the patient
- Patients in a persistent vegetative state (PVS) (equivalent to the German notion “Wachkoma”), i.e. with extensive and irreparable brain damages. Although vital functions (respiration, circulation, ability to receive nutrition) are in place, patients are completely dependent on nursing, and lack any consciousness of the “self” and ability to interact with others. They might have periods where their eyes open, and retain reflexive responses and responses to pain (this is therefore different from brain death, where all brain functions and circulation in the brain have ceased).
- Comatose patients, i.e. those who do not respond to any kind of stimulation, with closed eyes, no consciousness of self or surroundings. Surviving comatose patients rarely remain in this condition more than 2 – 4 weeks. The prognosis is

otherwise likely to be irreversible and without prospect of improvement.⁶

5.2 Ethical discussion: indications for withdrawing/holding treatment

The main concerns regarding abstaining from life-prolonging treatment are of two kinds: one related to the assessment of situations or type of indication that allow for (dis-)continuing treatment, the other related to decision-making – in particular how to incorporate the will of the patient. The first kind of concern activates questions related to quality of life and to the potential distinction between care and treatment.

Quality of life and abstaining from life-prolonging treatment

One fundamental concern in medical ethics that enjoys wide support is the idea that severely burdensome, painful and distressing medical treatment is justified only when the burden is outweighed by the good or benefit it brings to the patient. Treatment that is excessively burdensome and painful without generating a proportionately larger good for the patient cannot be defended. This principle applies also to life-prolonging treatment at the end of life, in the sense that treatment which is only conducive to a patient's continued pain and distress, yet

⁶ These distinctions are taken from the proposed guidelines for life-prolonging treatment by the Norwegian Directorate of Health (Helsedirektoratet 2008)

does not do any good for the patient either curatively or palliatively, is difficult to justify.⁷ This implies an evaluation of how treatment affects the patient's quality of life for the better or for the worse, where treatment that results in a lowered quality of life than abstention from treatment would give is problematic. Within Christian ethics and church statements there has been certain reluctance about using references to quality of life, based on a suspicion that they imply a claim that human life falling below a certain threshold of quality is not worth living. To the extent that such a claim is implied, arguments from quality of life are indeed problematic. But at this point quality of life is not used to assess whether a human life is worthwhile or not, but whether a certain treatment is worthwhile (Keown 2002:44). It is not an assessment that a particular human life is not worth living, but an argument that in a given situation a human being's condition is not improved, but in fact worsened by receiving a certain medical treatment,

⁷ E.g. a recommendation on palliative care prepared by the European Health Committee adopted by the Council of Europe Committee of Ministers states that palliative care should neither hasten nor postpone death, and demands that "technologies available in modern medical practice are not applied to prolonging life unnaturally", and that "doctors are not obliged to continue treatments that are patently futile and excessively burdensome to the patient" (CoE Committee of ministers 2003: no. 50). However, the recommendation does not go further into what might constitute an "unnatural prolonging of life", or when treatments have become "patently futile and excessively burdensome". These decisions are left to be spelled out in more detailed guidelines, or to clinical and medical-ethical judgment.

compared to forgoing it, and that this treatment is therefore unwarranted.⁸

This consideration indicates that life-prolonging medical treatment which simply postpones death with a few days or weeks, but makes the remaining life span more painful and troublesome than it would otherwise have been, should be withdrawn or withheld. Not only might it harm the patient by increasing pain, distress and discomfort associated with intensive medical treatment. It might also, by diverting the patient's attention and remaining energy into receiving medical treatment, frustrate their possibility to prepare for death, to conclude the narratives of their lives, become reconciled with their surroundings, and come to terms with their fear, trust and hopes in face of death. The treatment apparently does no good, but prolongs an inevitable, troublesome and eventually unstoppable process of dying, adding to its pain, burden and distress. Keeping in mind the description above of the ingredients of palliative care at the end of life, intensive medical treatment that merely extends a dying process filled with pain and distress without providing any relief, comfort or alleviation, in fact conflicts with caring properly for the dying.

⁸ This distinction between using quality of life in relation to assessing whether treatment is worthwhile or not and assessing whether a human life is worthwhile or not is also the reason why this argument regarding quality of life is not considered valid in relation to euthanasia, where it does in fact become a matter of assessing whether or not a human life is worthwhile or not.

Regarding the other possible indications listed above, this assessment concerning how (dis-) continued life-prolonging treatment affects quality of life is more complicated. Some doubt that there is any benefit to be had from treatment that prolongs a life under conditions as they are described here. Can treatment that does nothing except prolong a life deprived of essential functions be worthwhile?

On the one hand, as stated above, maintaining biological life and maximising its length is not in itself an absolute good that in all situations overrides all other concerns. On the other hand, when being human is understood as receiving life from the loving hand of God and being called to respond to God as well as to the surrounding world for life, it is equally clear that quality of life is not simply the net sum of pleasure over pain, or of satisfied preferences over unsatisfied ones. Quality of life must be viewed in relation to human life's basic characteristic of dependence, and its basic qualification of somehow responding to this dependence and the good that is received through it. In this perspective quality of life is very well compatible with a life that does not possess features such as control, intentionality, rationality or subjective activity, or a persistent sense of self, for example because of severe brain damage, disability or dementia. Also these forms of life, even though they might lack the capacity for agency in the usual sense of the word, might still be able to relate to things in their surroundings with at least some degree of awareness and response to sensory impulses, such as touching, sounds, light and the like. And life that has not yet developed or has temporarily lost the capacity for this kind of awareness and response might (re-)gain them. Treatment that upholds this kind of life might therefore very well benefit the patient in the sense that his or her quality of life is better off with than without

treatment. There are other forms of exercising responsible life as life in response to what is received from the hand of God and from the world surrounding us than a biography expressing itself through self-assertion, control, intentionality and rationality.

However, this is different from human life that exists merely as a biological entity, where capacity for awareness has been entirely and irrevocably lost, the typical case being most patients in persistent vegetative states (which as presented above are different from comatose patients). Even under these circumstances human life is still the object of God's love, and might still be the object of the love of close ones such as family and friends, surrounded by human community. But what seems to be lacking is an essential precondition for responding to that love, through receptive and sensory capacities in the form of awareness, not only temporarily, but permanently and irrevocably. In this situation it is less clear how life-prolonging treatment benefits the patient.

A distinction between care and treatment?

Some approaches, prominently exemplified by the papal allocution from 2004 by John Paul II, claim that a distinction must be made between treatment and care, between medical procedures and natural means of preserving life, between extraordinary means and ordinary means of intervention. Medical procedures or extraordinary means of intervention might be withdrawn or withheld when they become futile and burdensome to the patient. Natural means of care, however, respond to the most fundamental needs of all human beings, something on which we all depend, and of which no human person should therefore under any circumstances be deprived.

The merit of this distinction partly depends on how one defines care / ordinary means as distinctive from medical treatment / extraordinary means. Whereas life-prolonging, “extra-ordinary” treatment is widely agreed to include procedures like antibiotics, respiratory assistance and dialysis, “ordinary means” typically involve basic care such as hygiene, tending to bedsores, hydration, and relief of physical and psychological discomfort. In most cases they prevent the patient’s discomfort from escalating and becoming unbearable, and are therefore not only morally but often also legally warranted and required.

The question how to categorise artificial nutrition has been more contentious. Whereas regulations in many countries and clinical settings list it as a life-prolonging treatment that could be stopped when no longer warranted, the above-mentioned papal statement reinforces Catholic teaching by saying that nutrition is also an ordinary means of basic care, never to be stopped as long as the patient is still able to digest the food.

Several remarks are relevant here. First it is important to keep in mind the unbroken requirement of Christian teaching to care for life when cure or improved medical condition is no longer possible. All human life, even that of the incurably and terminally ill, is owed basic care, not because that might be instrumental to its recovery and medical cure, but because it is reflective of the status, dignity and demand for respect that surround every human being by virtue of being God’s loved creation. Not removing basic care for human beings thus has a very strong presumption in Christian ethics, and this also brings into the discussion issues about how to treat patients without hope of recovery from serious illness or trauma. This presumption in favour of not forgoing basic care, including nutrition, cannot be disconnected from the link between care

and the patient's fundamental welfare. It is because these forms of care typically are conducive to the relative comfort and wellbeing of the patient in the midst of serious and terminal illness, also where no hope of recovery or improvement exists, that the obligation to care carries moral weight. Although there is a strong presumption in favour of maintaining care, including nutrition, this should not be made absolute and disconnected from considerations of how the patient is in fact affected by continued care, and whether or not it simply exacerbates and prolongs patients' distress and pain without benefiting them.

The risk of over-treatment

It is not only the question of when to refrain from life-prolonging treatment that involves deep moral questions and risks of harm to patients, but also there is the risk of "over-treatment". Over-treatment involves a considerable risk of moral harm to patients, and is perhaps a larger problem in clinical settings than unjustified withdrawal of treatment. It happens when misplaced eagerness to do the most for the patient leads medical doctors to focus exclusively on introducing and trying out ever-new medical treatments, even when the patient is approaching a terminal phase, and the likelihood of any curative or palliative effect is almost nil. Regardless of whether this is prescribed out of professional zeal or genuine but misplaced compassion for the patients, this kind of treatment might cause serious harm to the patient.

Not only can it inflict severe pain and affliction by introducing operations that require painful rehabilitation and perhaps leave the patient hooked up to medical technology for a lengthy period of time, but also such medical therapies can have significant and agonising side-effects. By diverting a patient's

focus and remaining resources, attention and concentration into undergoing and receiving medical treatment (perhaps absorbed in new hopes and expectations) it might also impede their coming to terms with their own death, processing their life-story, relations, place in the world, hopes and beliefs. In short, it might prevent the patient from becoming reconciled with death. As such, this kind of over-treatment might also do harm to family and relatives, who are deprived of any possibility to depart in “peace and quiet” with a loved one, who instead is immersed in medical treatment and technology.

Nor should one overlook the effect on patients’ as well as the general public’s trust that, should they arrive in a state of terminal illness, they will be properly cared for as human beings, not merely objectivised as medical cases that might respond to curative attempts.

It must therefore be underlined that not only is it permitted not to do all things medically possible for a patient whose life is approaching its end. It might very well be required not to continue medical treatment when targeting a physiological illness, and instead direct resources, knowledge and energy to care for the patient as a person with emotional, psychical, spiritual dimensions in addition to the physiological.

5.3 Ethical discussion: The will of the patient

Medical ethics has a strong presumption in favour of not treating anyone against their will, a presumption that can be supported from within a Christian, Protestant tradition. Accordingly, the patient’s will is obviously essential when assessing whether or not life-prolonging treatment should be

discontinued. This evokes the question about how best to incorporate the patient's will when it cannot be known directly.

Patient's expressed will

In some cases the patient's will can be obtained directly. Patients are conscious, well-informed and aware of their situation, and can explicitly state their will regarding a therapeutic intervention that might prolong their lives. Medical ethics views autonomy in general, and the principle of informed consent in particular, as fundamental. Provided that patients are 'of sound mind', not suffering from mental illness nor deluded about their situation, it is considered a serious violation to subject them to treatment they have not consented to, and even more serious to subject them to treatment they have explicitly resisted and rejected. Autonomy in this sense of being free to resist unwanted intrusions on one's life and body is also a vital concern from a Protestant perspective, as it protects personal integrity and enables responsibility.

This basic standard of informed consent as a necessary precondition for introducing medical treatment holds also for vital, life-prolonging treatment. Well-informed and competent patients are entitled to have their decisions respected when they resist further medical treatment, even if it implies that the patient's life is shortened.

However, when it comes to life-prolonging treatment, the patient's will often cannot be directly obtained. How can such situations be dealt with?

Advance directives

One instrument is the so-called *advance directive*. A declaration is signed by a person still ‘of sound mind’ stating his or her will regarding life-prolonging treatment if, as a consequence of future incurable illness or trauma, he or she can no longer have any conscious experience of life, or continued life will be marked by severe pain, permanent impairment and helplessness.⁹

This raises the question of whether a directive or wish expressed *in advance* should be binding for the decision taken by medical personnel. The question revolves around whether persons can in fact make truly informed and autonomous choices regarding a potential, future state of severe illness or injury. Can individuals know beforehand how they will experience a life in such a state, and can they know what their central values and wishes will then be? Many agree that advance directives should have considerable weight regarding life-prolonging treatment. An objection against viewing them as absolutely binding, however, is that they do not allow for changes in individuals’ sets of beliefs, values and their overall evaluation of life. One way of taking this into account is to require that there are no reasonable grounds to believe that the directive no longer expresses the will of the patient.¹⁰ Another

⁹ Formulations taken from Norwegian version.

¹⁰ Recommended by the World Medical Association statement (2003).

way would be to require that directives are backed up by “renewals”, for example to be reaffirmed annually.

There seem to be two somewhat different approaches which can be taken to advance directives and the question of their being binding expressions of a no-longer competent person’s will. One is to view them in contractual or legal terms, establishing a set of rights and duties on the part of patient and doctor respectively, and exempting doctors from allegations of wrongdoing if they comply with the directive. The other is to view them as one factor among several in ascertaining the patient’s will. An advance directive would then be essential, and increasingly so the more recently it has been affirmed, but it would not be the only factor in establishing the patient’s will.

Patients ‘not of sound mind’/Incompetent patients

In some situations patients are unable to form and / or express their wishes, but have not previously issued an advance directive. How can a responsible decision regarding life-prolonging treatment then be made? The only solution seems to be to try as far as possible to access the patient’s wish indirectly, in combination with a medical assessment of the patient’s best interest.

Family members

Trying to verify the patient’s wish in such cases typically involves some sort of proxy who attends to the patient’s interests. Often this is a close family member, for example a spouse or partner, an adult child, a parent or a sibling. Knowing the patient closely for a long time they might have talked about this kind of situation and what the patient would have wanted.

Or they might know the patient's more general beliefs and values, and from them be able to infer what the patient would have wanted. Furthermore, they can normally be expected to have the interests of their family member at heart.

Thus there might be good reasons to view family members' opinions as important in the decision regarding treatment. However, several points should be noticed in this connection. First, there must be no reason to suspect that the family member/proxy in fact has little knowledge of the patient, and / or does not have the patient's best interests at heart. Secondly, there should be extensive and careful communication between doctors / health-care personnel and family members, to ensure that the family is involved in the decision-making process. Lastly, the final conclusion should rest with the doctor. Family members should never be burdened with the final decision to end treatment of a loved one. In addition, particular caution should be exercised by responsible medical personnel in cases of disagreement between family members over the question about continuing treatment.

Legal guardian

In some cases the proxy might be an appointed legal guardian (e.g. a lawyer) who is legally entitled and obliged to attend to the patient's interests. This person can be appointed by the patient himself or herself before the state of incompetence arises (parallel to the advance directive), or after incompetence has occurred. This might be done for several reasons: for example if there are no close family members; if the patient does not want family members to speak on his or her behalf in situations of incompetence; if the circumstances in the family make members unfit or unable to attend to the patient's best

interests; or if the patient or the family want to distinguish between the formal role of legal guardianship with being a loving and caring family. Unless there is reason to believe that family members do not know or do not care about the patient's wishes and best interests, it might also be appropriate, when there is a legal guardian, to consult with family members.

Precisely because the final conclusion rests with the doctor, it is important that before reaching this final conclusion the medical doctor responsible has communicated and consulted as widely and relevantly as possible in order to determine as best he or she can which decision complies with the patient's wishes, and serves the patient's best interests.¹¹

Good processes of communication and deliberation conducive to responsible and good care for patients 'not of sound mind' regarding potentially life-ending decisions should be: a) transparent: to family members and relatives, to health-care personnel and the doctor responsible, and to the general public / prospective patients, in the sense that it is known who will and should be consulted, and what status their advice will carry; b) inclusive: in the sense that all professions/groups/units and personnel involved in the treatment of the patient are involved (different groups such as medical doctors, nurses, counsellors might have different knowledge and information regarding the patient's values, beliefs, intentions), and that family members are involved in a relevant way, receiving sufficient information

¹¹ One might also question whether the final decision should in fact be lodged with an independent committee or board, rather than with the responsible doctor.

and being invited into a deliberative process; c) given sufficient time: as far as possible avoid the decision-making process being unduly accelerated for reasons of resources or expediency. One should be especially aware of and attentive towards family members who are striving to come to terms with the approaching death of a seriously ill or injured loved one, and the impact and prospects of this situation on their own lives as well as on the patient's. Sufficient time should be given for deliberation, counselling and support – also in the context of the congregation – for family members, listening to their worries and concerns and helping them come to terms with the situation and the prospective loss of a loved one before a conclusion on life-prolonging treatment is made. Special challenges arise when the patient in question is a child. In such situations it becomes particularly important to allow family members, who might be parents, sufficient time and communicative space to come to terms with the traumatic situation of not only losing a child; they must also be able to see how that loss is intertwined with a decision to terminate medical treatment, and they must be allowed to be involved in that decision themselves.

Discontinuing or withholding life-prolonging treatment: Conclusion

Discontinuing or withholding life-prolonging treatment under given circumstances is not only permitted, but might in fact be required as an element of proper care and compassion for a seriously, irrevocably or terminally-ill patient. This is in any case true whenever continued treatment does not do the patient good, curatively, palliatively, or in terms of sustaining a life that has quality in the Christian sense of being able to receive, sense and somehow respond to a love given. A consistent Christian

tradition emphasises the duty to care for the seriously ill and dying, even when there is no longer any hope of cure or improvement, and thereby yields a strong presumption in favour of maintaining measures of care that can alleviate pain, discomfort and distress in life's final hours. On the one hand, medical, clinical and nursing measures of care, whether life-prolonging or not, are vital moral responsibilities that have a very strong claim on us and cannot easily be set aside in favour of other concerns. On the other hand, they are not absolute requirements, elevated above any consideration of the implication they will have for the patient and his or her situation. This concretely implies that Protestant churches, although recognising the complex moral dilemma and assessment and the heavy moral concerns involved, are not, for example, prepared to reject as always and absolutely wrong the discontinuation of nutrition to patients in persistent vegetative states.

Moral concerns and evaluations pertain not only to the decisions, but also to the process through which a decision is reached. The patient's well-informed and explicit wish against further treatment should be respected, and when a patient 'not in sound mind' has previously issued an advance directive concerning treatment, this carries considerable weight, especially when there are no reasons to believe that it no longer represents the patient's will. In cases where there is no advance directive and the patient is irrevocably incompetent, communicative and consultative processes to reach a decision become particularly essential. They should be inclusive, involving a sufficiently broad spectrum of professions, health-care personnel and counsellors. Close family members, relatives

and friends who know the patient well and can reasonably be expected to have the patient's best interests at heart should be thoroughly consulted and given sufficient time and space to come to terms with the decision as well as with the prospective loss of a loved one. They should not, however, be burdened with the final decision.

6 Palliative care, treatment and sedation

An argument frequently used by proponents of legalisation of euthanasia and assisted suicide, is that there are cases where the patient sees no other feasible way of coping with his or her situation than being allowed assistance in ending life. Those who disagree often refer to alleged benefits of palliative care as an alternative. But palliative care might present questions of its own, and it is therefore necessary to consider it more closely.

Palliative medicine is, as mentioned above, defined by the World's Health Organisation an approach to improve the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering, including treatment of pain as well as physical, psychosocial and spiritual problems (cfr. above, pt. 4.4). It addresses a much wider spectrum than merely to alleviate symptoms typically occurring in the last phases of life. It seeks to accompany the patient for the last phase of their life-span, searching for ways of improving their quality of life.

Palliative medicine and care have undergone considerable development in recent years. There has been an intensified focus on interdisciplinarity and the involvement and contribution by different professions, and psychosocial and spiritual dimensions have been included to the understanding of serious illness, in addition to its physical dimensions. Knowledge, understanding and practice have improved as a result of extensive research programmes, and the subject is gradually incorporated into the education programmes of medical doctors. Churches ought to advocate that priority is

given to this field in our health care services as well as in medical training and research.

Although these welcome developments have changed the context of end-of-life questions in general and of euthanasia and assisted suicide in particular, as we will discuss in more detail below, it is not an easy solution that makes all difficulties and ethical dilemmas go away.

But one question that has to large extent become obsolete as a result of the improvements and developments to palliative medicine is the tradition question, familiar from many textbooks in medical ethics, about intensified painkilling treatment that might as a side-effect hasten death. Although widely accepted, the question about how to distinguish between this kind of medical treatment and euthanasia, and why the first could so easily be accepted whereas the latter apparently not, haunted ethical debates for years.

Today however, this question has lost much of its grip. Developments in palliative medicine and improved treatment of pain symptoms, implies that effective painkilling treatment is unlikely to have a life shortening effect. In fact, it often has the opposite effect of prolonging life, and with an improved quality.

Relieved of severe pain and distress, the patient might for example relax and sleep better, be less exposed to mental and physical exhaustion, and experience a heightened quality of life, which together prolong rather than shorten life. This is a strong case for increasing rather than being sceptical towards effective, pain-killing treatment.

In spite of the considerable improvements of palliative medicine and care, there are extreme cases where dying patients suffer excruciating pain, dyspnoea, nausea, agitation and spasms that are refractory to all kinds of treatment. This has evoked the question whether palliative sedation to reduce the patient's consciousness would be acceptable. Palliative sedation can tentatively be defined as induction and maintenance of sedation (by medication) for the relief of pain or other types of suffering in a patient close to death, with the exclusive intention to relieve intractable pain. The depth of sedation as well as its duration would vary depending on the patient's state, but the intent would be palliation, not termination of life.

Conditions for this procedure would typically be that the patient was expected to only have a few more days to live, although prognostic evaluations are difficult and must be based on the physician's best clinical view, experience and collegial consultation. All relevant diagnostic work should have been completed in order to distinguish between side effects of treatment and symptoms of illness, and all other relevant treatment tried. Furthermore, all relevant medical competence, such as expertise in palliative treatment should have been consulted. Also, thorough psychiatric evaluation should be carried out in order to deal adequately with psychiatric symptoms known to occur in life's terminal phase and responsive to other forms of treatment.

Having obtained the patient's informed consent, either directly or by proxy, obviously itself a challenge in these situations, the intentional sedation of a patient in order to spare the conscious sensation and experience of unmanageable and excruciatingly painful symptoms, is hardly unacceptable.

It is worth noticing that reports indicate firstly that there is little evidence that this practice is life-shortening. As effective palliative treatment in general, it seems to be life-prolonging rather than life-shortening. Secondly, the procedure seems to be rare and performed in extreme cases only, especially as competence in palliative care is growing and pain management and alleviation of symptoms improve.

7 Euthanasia

7.1 Defining the question

The discussion above suggests caring for the dying in some occasions involving withdrawing or withholding life-prolonging treatment. The pressing and unresolved question, however, is of course whether euthanasia and assisted suicide can also be a part of this repertoire of caring for the seriously ill and dying patient. Turning first to the question of euthanasia, the related but different issue of assisted suicide will be dealt with in the following chapter.

Although definitions of euthanasia cannot be separated from a theoretical and normative discussion of the subject, the following description covers the most typical and paradigmatic cases, and is therefore useful for the following discussion: “A doctor intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request”¹² (EAPC 2004).

When discussing euthanasia, two dimensions of the issue should be distinguished from each other. One dimension addresses euthanasia as an ethical issue and deals with questions such as interpreting the phenomenon within a more comprehensive framework (for example such as the one outlined above) and the normative justification for the practice,

¹² Developed by European Association for Palliative Care 2004.

exploring whether normatively valid grounds can be given in support of or opposition to euthanasia. Another dimension addresses it as a legal issue, asking how euthanasia should be dealt with in legislation and in public policies. It is important to notice how these two dimensions, although obviously not separate, are not identical. Legislation does not determine which ethical claims are normatively valid and legitimate, nor can what is ethically normative be directly translated into legislation and political regulation.

7.2 Ethical discussion

At face value there seem to be strong reasons not to accept euthanasia from a Christian, Protestant view: it appears as a direct ending of another person's life, and one that is not covered by the exemptions from the prohibition against killing that Christian ethics have typically accepted (self-defence, or defence of a third party). And it appears to violate the fundamental status of human life as inviolable, rejecting the obligation not to harm or destroy human life. That euthanasia apparently conflicts with these fundamental moral norms, seems to provide a strong presumption against accepting it. Could there, in spite of this apparent presumption, be valid ethical reasons that justify euthanasia?

Those who argue in favour of euthanasia typically refer to a combination of two types of reasons: first, autonomy and second, beneficence, (or the patient's best interests). Both are deep-seated and widely acknowledged moral concerns and are reasonably taken to be valid ethical ideals. Do they in fact provide a well-founded and valid argument that overrides the above-mentioned presumption against euthanasia?

Autonomy and euthanasia

The notion of autonomy plays a prominent role and frequently surfaces within medical ethics. It is, however, a complex notion with several different meanings not always easily distinguished from each other. Within secular, philosophical medical ethics, two somewhat different meanings of autonomy prevail. They are both relevant to the discussion of euthanasia, but often lead to different conclusions. A Kantian conception understands autonomy as self-legislation and the ability to act according to a rational law of universal principles, rather than according to contingent impulses or external pressure. Moreover, it is the capacity for this kind of autonomous action that defines an end in itself, and which therefore commands that a human being is always also treated as an end in itself, and never only as a means to an end. Another conception of autonomy sees it as the ability to act from one's inner preferences, interests and projects. Autonomy thus understood allows the human being to express and realise inner potential and act according to individual aspirations and values. Autonomy as it features in secular medical ethics is certainly not irrelevant to protestant ethics, but another notion is more fundamental, namely the notion of freedom. This notion refers to human being as basically defined through the relation to God rather than through worldly, external authorities. As justification by faith sets human being free from the project of realising life's ultimate meaning through moral efforts and performances, she is thereby also set free to serve the neighbour in responsible love and care. A protestant notion of freedom is therefore firstly based in a preceding and more fundamental dimension of gift, reception and dependence. Secondly, although freedom is given by God and never to be realised or manifested in moral performance, neither can it be disconnected from responsibility.

One should first be aware that accept of euthanasia is not the unequivocal inference even from the secular or philosophical concepts of autonomy. Several commentators would deny that the Kantian version of autonomy as self-legislation and the ability to act from a rational, universal law, justifies euthanasia. A practice of euthanasia would as they see it, conflict with a basic moral duty never to treat humanity, whether in one self or in someone else, only as a means, but also always as an end in itself. It would undercut the very condition for autonomy, namely the existence of a human person. Others, however, might be more prone to start with a set of basic rights that should be absolutely respected by others, and include in that set also the right to receive by a consenting other assistance in dying. That, however, still leaves the paradoxical question how there can consistently be a right to eliminate oneself as a holder of rights.

The notion of autonomy as self-determination and the possibility to pursue one's aspirations, interests and preferences, is more uniformly used to back up justification of euthanasia as a morally acceptable practice. Assuming this notion of autonomy, is this a convincing argument in its own right? At least it evokes some questions. Firstly, there is again the question about the range of autonomy. Does it stretch as far as to determine its own destruction?

Some interpretations of autonomy claim that it cannot be used for decisions that will in the future reduce or destroy autonomy in the sense of the person's ability to be self-governing. Furthermore, some will doubt the possibility of obtaining with any certainty the consistent and firm wish of a seriously and perhaps terminally ill patient. Studies have shown that seriously ill and dying patients' wills to live fluctuate considerably

(Chochinov et al.); furthermore, several conditions that are likely to occur for patients in this phase (fatigue, anguish, depression) might reduce autonomy in the sense of capacity to make an informed and considered, intentional decision, unimpeded by external influence (Johansen, Materstvedt et al.). To this, some might object that it is inconsistent to accept that the patient's autonomy is given so much weight in decisions concerning abstention from treatment (cfr. Above, ch. 5), but is viewed with such suspicion when the question is about euthanasia. One answer is that the autonomous decision to *resist* intervention and infringement, for example in the form of unwanted medical treatment, weighs heavier than an autonomous claim to receive certain forms of service, assistance, help etc., such as assistance in dying. Also, studies have shown how requests for euthanasia in terms of direct and intentional shortening of life to a large extent respond to palliative care and treatment, in the sense that direct requests for euthanasia decrease considerably, whereas requests not to receive life-supporting treatment seem to continue (Neudert et al, 2001). However, it should also be noticed that some requests persist, even after having received what is considered to be adequate palliative care. This indicates that although improved, effective and adequate palliative medicine and care can to a large extent affect requests for euthanasia, it will not eliminate these requests altogether.

In addition to this internal criticism, a Protestant approach might question these philosophical notions of autonomy in the first place, based in a quite different concept of freedom as prior to an ethical concept of autonomy. Protestant tradition, as elaborated above understands freedom as grounded in human being's relationship with God in creation and justification, whereby a human being receives life from the hand of God.

Thus freedom is intrinsically associated with, though not conditioned by, responsibility and the calling to respond to God for the life received through the His hand. This notion of freedom is clearly not equivalent to self-determination or self-governance of a life owned by oneself, but is connected to responding to God for the life one has received. It questions the use of autonomy to justify euthanasia, claiming that freedom does not entail absolute self-governance or self-ownership, but is inextricably connected to responsibility for one's life to oneself, to others, to the created world, and ultimately to God.

Beneficence and euthanasia

Those who accept that there are situations where euthanasia might be permitted often argue that in cases where the patient is in grave pain and suffering and has no hope of recovery or alleviation, it could be in the patient's best interest to have life ended. Provided this is what the patient explicitly wants, he or she should then not be denied access to euthanasia.

Whether or not a patient can benefit from euthanasia cannot be decided without considering available alternatives. Studies of patients' reasons for requesting euthanasia indicate that physical pain alone is rarely the reason; rather, it tends to be combined with reasons related to psychological pain, such as loss of sense and meaning, a sense of having become a burden, or of experiencing an undignified state of life.

This corresponds with studies suggesting that patients prefer so-called individual quality of life - scales, that is, scales of quality of life informed by their individual preferences, aspirations and values (Neudert et al, 2001). Patients' experience of severely reduced quality of life, potentially leading to requests for

euthanasia, are likely to ensue from a combination of factors which not only comprise the physical dimensions of illness and corollary symptoms of pain, but also other dimensions such as social and existential dimension. Palliative medicine and care better able to address the width of dimensions to patients' individually perceived life quality would thereby also be better equipped to respond to and diminish requests for euthanasia.

Adequate responses to the question of euthanasia must also be sought along lines that correspond with the context-dependence and self-interpretive character of the reasons for requesting euthanasia. Self-interpretation, how one perceives and understands one life as having (or lacking) a particular meaning and as formed around certain narratives, is also mediated through resources available in the surrounding culture and society: for example images, symbols, metaphors and value-systems through which we frame our visions of human life and understand social interaction. Viewing one's life as being undignified and unworthy in a state of serious and terminal illness, being completely dependent on the assistance and care of others, unable to display and control basic human characteristics and functions, is an interpretation also mediated through the resources made available by the patient's surroundings. A response to a request for euthanasia in this situation that simply takes the patient's self-interpretation as experiencing an undignified end of life as a given fact does not go far enough. It is necessary to explore possibilities for finding and establishing resources that enable a different view of the self in life's terminal state. The already mentioned highly improved possibilities of palliative medicine and care take us a far way in this direction, and it is therefore vital that churches advocate further increased efforts in this area. At the same time, it should also be said that palliative care will not solve all

dilemmas and problems in this field. There might be patients suffering from intractable pain, and in particular there is likely to be patients who will continue to perceive their life and their state of terminal illness as insufferable, unable to find any relief or value in it. Different patients might assess situations that as far as the medical and physical dimension is considered are relatively similar, highly differently in terms of individual quality of life.

In this connection a particular concern should be mentioned. Statements on end-of-life decisions from Protestant churches occasionally state how illness, pain and suffering are an unavoidable and inescapable part of human life as we know it. Correct as this may be, this claim is sometimes used argumentatively in ways that give cause for concern. They rarely explore the potential significance of distinguishing between suffering that can in fact be avoided or at least reduced, and suffering that is resistant to human action and alleviation. That the very phenomenon of suffering, including illness and physical pain, will always be present in this world as we know it does not reduce the obligation to do what is possible to alleviate and remedy that physical pain which can in fact be helped. Although some seriously ill persons who go through grave pain and suffering might be able to discover meaning even under these conditions, there are no grounds for glorifying or even affirming illness and pain as integral to human life. For many – patients and relatives – serious illness and approaching death appear as utterly painful and meaningless. Churches should not dismiss these experiences or escape the moral challenges they represent by too soon taking refuge in the assertion that illness, suffering and pain are an inescapable part of life and can be places of meaning.

A Christian, Protestant view of human life underlines how dependence on the care of others – health-care personnel, family or friends – is not an inauthentic or undignified form of human existence. Dependence is better described as an inescapable characteristic of human life, closely connected to the fact that life is not self-acquired by human beings, but received from sources external to ourselves. Thus not only is experience of dependence compatible with manifestation of dignity in human life, it might also remind us of one of the fundamental conditions of human life under which we all live, which is its fundamental and inescapable relationality. It is an important task for churches to make these interpretive resources available to seriously ill and dying people, allowing and encouraging a self-understanding of life as manifesting human dignity. This underlines the importance of developing and giving political priority to palliative care in all its forms, be it in hospices, palliative care units, nursing-home teams, or in day care.

By seeking to alleviate not only physical pain but also psychological distress, social and relational challenges as well as spiritual problems related to lack of meaning and hope, good palliative care contributes greatly to patients' possibilities for experiencing end of life as a manifestation of dignity rather than a lack of worthiness. At this point the Protestant churches in Europe want to recall the Council of Europe Recommendation to its member states on the organisation of palliative care (Council of Europe 2003). The studies conducted in connection with this report document a widespread interest and energy around Europe in establishing palliative-care services, but also that there are "considerable differences in the extent to which palliative care is available to those who need it" (Council of Europe 2003:22). Among the recommendations worth

reiterating is that which calls on governments of member states to “adopt policies, legislative and other measures necessary for a coherent and comprehensive national policy framework for palliative care” (Council of Europe 2003:8).

Euthanasia and refraining from treatment: relevant difference

An argument frequently used by those who believe that euthanasia can be morally acceptable is that there is no morally relevant difference between withdrawing treatment and euthanasia, and that it is therefore inconsistent to accept the former but reject the latter. This argument seems to rest on the assumption that as the outcome – the patient’s death – is the same in the two situations, the situations are similar with respect to their morally relevant qualities.

However, outcomes are not the only morally relevant qualities of situations like these. Another aspect frequently referred to in order to justify a difference between euthanasia and withdrawal or withholding of treatment, is *intention*. Whereas the intention when treatment is withdrawn is to avoid a prolonged process of dying, causing the patient grave pain without any other positive effects or improvement of his or her situation, the intention of euthanasia is to end the patient’s life. But using intention to justify this distinction in moral quality faces some problems. First it is somewhat problematic to handle in practice. Our intentions are porous and flexible rather than fixed and stable, they are largely open to construction according to our desires and needs, and they are to a certain extent also opaque to ourselves. Whether or not my intention at a given point really is to withhold treatment considered to be futile prolonging of a patient’s death, or whether it is to put an end to the patient’s

misery, can not necessarily be firmly established. And moreover, to the extent that it can, intention is rarely considered a decisive criterion for deciding on an action's acceptability. An otherwise objectionable action is rarely considered justified and acceptable simply by the argument that the intention was good.

Another and more convincing argument consistent way of justifying this difference between euthanasia and abstention from treatment, is the distinction between "action" and "omission". It makes a moral difference whether a specific situation – say, a person's death – arises through a person's omission or through a person committing an action. There is, so the argument goes, a relevant difference between doing something, and merely allowing it to happen. Here the difference is not connected to a difference in the agent's subjective state of mind, but based on a difference in the agent's objective involvement through his or her actions and intervention. "Doing" and "allowing" is not the same when it comes to moral evaluation, even if the outcome is the same in the two situations. The point is that we are responsible not only for results that come about, but also for involvement in how they come about through our action and conduct. It is not indifferent to moral evaluation whether something happens as a result of me not intervening, or whether it happens because I do something. Clearly, there might be situations that can be construed in a way that merely having not intervened does not make the person less blameworthy than had he acted directly. A passive bystander will not escape moral blame for allowing a child to die by not intervening when the infant slid under water in the bathtub. But such examples do not resemble the distinction between withholding life-prolonging treatment and euthanasia. Moreover, they do not erase the fact that our actions, practices and conduct matter morally, not only the

results that emerge from them. Some of the Protestant churches have used this distinction between “awaiting” death and “hastening” death as a tool to explain the difference they see between refraining from further, futile treatment, and euthanasia. This distinction captures an important dimension to an adequate idea of moral subjectivity and agency.

Euthanasia and societal effects

In addition to these objections against the arguments of autonomy and beneficence in support of euthanasia, it is not uncommon to refer to a concern for the potentially disruptive societal effects of legalising euthanasia. Some fear a slippery slope effect where euthanasia becomes a widespread solution in cases where the end of life occurs through serious illness. Irrespective of whether one accepts the “slippery slope” as a valid form of ethical argumentation, documentation from the national legislation with the longest experience of allowing euthanasia – Netherlands – indicates a steady increase since 2006. Reported cases 2006 were 1900, in 2010 were approx. 3100. Before 2006, however, there seemed to be a drop in number of cases for a few years, so the picture is not unequivocally one of a steady and continuous increase. Also, one should keep in mind that it is still a rare cause of death, almost exclusively occurring within the realm of terminal cancer, in patients expected to live for no more than a few weeks. Doctors appear to experience euthanasia as an unusual and burdensome aspect of their practice, and not something they take lightly or grow accustomed to. Societal effects could be measured by various indicators. One would obviously be the occurrence of euthanasia in terms of annual cases. In that case the Netherlands seem to provide a case for concern that it is difficult to contain the number of cases. On the other hand, one

could measure societal effects in terms of ability to ensure compliance with legal regulations and overall sound practices, in which case the Dutch situation is probably not all that bad. It seems that the conditions that must be met for not prosecuting cases of euthanasia are usually met, and that the review boards set up to examine compliance in concrete cases, are in fact able to prevent malpractice and escalation of euthanasia for other reasons and in others ways than those determined by law.

Euthanasia and legalisation

The preceding section clarifies that Protestant churches find euthanasia ethically deeply problematic, for a variety of reasons. It conflicts with some of the most deep-seated moral convictions, not only of a specific Christian tradition, but of a wider common moral legacy, namely the ideal not to take innocent life and the duty to protect life, especially that which is vulnerable and frail. The arguments typically offered to rebut this basic moral conviction, namely from autonomy and from beneficence, do not carry weight as ethical justification of euthanasia. However, in and of itself this does not resolve the question about legislation and if euthanasia could still be legalised, in spite of the fact that it cannot be defended on grounds of Christian ethics. There are obviously practices and ideals condemned by Christian ethics which are still permitted by law.

The question of the legalisation of euthanasia is connected to the complex issue of the relationship between ethics and the law. Distinct from the question of its ethical acceptability, it rests upon whether euthanasia can be considered a matter where society, political rule and legislative power have a legitimate authority, or whether authority rests with the individual

conscience. Considering the question of euthanasia and whether to legalise it, the following concerns are important to consider. Most importantly, legalising euthanasia implies normalisation of a procedure to end the life of a seriously and irrevocably ill person with the approval of state and society. Irrespective of the claims by those who favour legalisation that there will be strict legal requirements and conditions, and it will be reserved for exceptional and rare cases only, this still implies introducing euthanasia as an element of ordinary legislation and juridical practice. This is a distinctively different solution from the one followed in certain situations by some nations and more far-reaching. In rare cases where doctors (or others) have openly admitted performing or have been known to perform euthanasia, prosecution has been waived on the grounds that, although a crime according to the law has been committed, it was clear that it was done at the request of the terminally-ill patient, in order to release, and with the effect of releasing, the patient from intractable pain and discomfort in the final hours of life. This possibility of the law not to prosecute in some extreme and very rare cases could be seen as an outcome of the double concern that 1) there can be situations where prosecuting seems a misplaced reaction, and 2) that the fundamental principle is still maintained that state-sanctioned ending of the life of seriously ill patients should not be normalised and made part of ordinary legislation. Having this opening might be a way of acknowledging the existence of moral tragedies, situations where a violation of either one of two or more very deep-seated and vital moral concerns cannot be avoided, and where, irrespective of what is done, a fundamental moral good will have been distorted. Acknowledging the possibility of moral tragedy is also entirely different from saying that the one solution is thereby ethically approved. The tragedy lies

precisely in the fact that there is no way of avoiding moral culpability.

Euthanasia: Conclusion

The Protestant churches are deeply concerned about patients and relatives who go through an excruciating process of serious and terminal illness and are awaiting death, realising that not only might our societies still be inadequately equipped to assist in their situations, but as communities of faith they might also still not offer the companionship, support, comfort and hope that is the calling of Christian faith. Confronted with this reality, there is reason to be mindful of these shortcomings in relation to patients and families before too quickly passing moral judgement. The basic calling, for societies, communities and churches, is to ensure that adequate care, comfort and alleviation of pain and suffering, are available and provided, and to promote communities and values that allow persons who are seriously ill and completely dependent to perceive life as containing an inviolable and unabridged dignity.

Protestant churches find euthanasia ethically problematic as a response to this situation, and for a variety of reasons. It conflicts with deep-seated moral convictions, not only of a specific Christian tradition, but of a wider common moral legacy, namely the ideal not to take innocent life and the duty to protect life, especially vulnerable and frail life. And the arguments typically offered to rebut this basic moral conviction, namely from autonomy and from beneficence, do not carry weight as an ethical justification of euthanasia. It is hard to reconcile with one of the most vital and persistent beliefs and commitments of the Christian tradition, namely that the fundamental and inalienable dignity of human life rests not in

its capacity for independent self-determination and agency, but in the creating and justifying love which a human being receives from God in Christ.

This cannot be viewed purely as a matter of individual conscience which the state ought to legalise. Legalisation would imply a kind of normalisation and approval of euthanasia, turning it into an ordinary and established element of medical and clinical practice. The fact that moral tragedies might occur, e.g. situations in which there is no way of avoiding deeply distorting an essential and vital moral good, could provide an excuse for a legal loop-hole – as has in fact been done in some countries – by not prosecuting in rare and extreme cases, and therefore not following the due legal processes.

8 Assisted suicide

8.1 Defining the question

Along with a limit to therapy, palliative sedation and killing on request (euthanasia), assisted suicide also belongs to the category of “end-of-life” decisions. Unlike euthanasia, in this case, death is not brought on directly by a third party, but by the person who wishes to die. The necessary means to do so, however, is provided by a third party. The typical case is when a doctor provides a patient with a lethal drug for the patient to administer him- or herself.

As presented above, legal regulations of assisted suicide vary a great deal in the European countries.

Some countries forbid both euthanasia and assisted suicide, whereas others, Germany and Switzerland being famous cases, make euthanasia a criminal offence, but not assisted suicide, provided that certain conditions are met (cfr. 2.3).

Above it was argued at length that we find no compelling grounds or concerns according to which the strong moral presumption against ending someone’s life through euthanasia could be set aside. The question therefore is whether assisted suicide is similar to euthanasia and must be rejected on the same grounds. If assisted suicide is not on a par with euthanasia, does that imply that assisted suicide can in fact be accepted in some situations? Also, if it is not the same as euthanasia, what does that imply for the evaluation of assisted suicide? At this point there is the question of a moral and/or a

legal right to suicide, and possibly a right to assistance in suicide for persons who are unable to carry out that action by themselves.

8.2 Assisted suicide and euthanasia

Those who believe assisted suicide could be justified, normally set up conditions similar to those frequently advanced with respect to euthanasia, and require that it be reserved certain situations and on certain conditions only. Chief among these are: that the person in question is seriously ill, without hope of recovery or effective curative treatment. The action of assisted suicide, like euthanasia, comes into consideration where an essential concern is to protect a seriously ill patient from further pain, agony and distress. It is an attempt to respond compassionately to a patient's suffering, anxiety, and physical and mental affliction. (We therefore also leave out of sight assisted suicide in other situations than serious and terminal illness, such as existential despair and hopelessness, or mental illness such as severe depression). And as with euthanasia, irrespective of whether one believes that it is a misguided response, it should be borne in mind how these actions are linked to concern, compassion and empathy for a seriously ill and suffering person. Consequently, euthanasia and assisted suicide are equally deaths prompted by and indissolubly linked with the most tragic circumstances. This inescapable context of the tragedy of human suffering and distress clearly compels us to refrain from hastening to moral condemnation, and in particular call for great reluctance in judging those who can see no other way through their agony and affliction than to seek death along these paths. Rejection of assisted suicide might as well involve and carry with it a moral burden that cannot easily be escaped.

A further qualification shared by euthanasia and assisted suicide alike is that a request for assistance must be voluntary and stable. There should be no pressure from spouse, family, friends, health care personnel, and other possibilities of cure as well as care should have been exploited and proved futile and without significant effect. As with euthanasia, this evokes the question how it can be ascertained that these conditions do in fact obtain. For instance, how can one establish with sufficient certainty that family-members – in spite of their having the best of intentions – are not behaving in a way that creates in the patient a sense of being pressed and controlled, or being led in a certain direction regarding the end of his or her life?

However, in other respects assisted suicide seems to differ from euthanasia. In cases of assisted suicide the action that brings about the end of someone's life is executed by that person, whereas in cases of euthanasia it is executed by another person. It is probably this difference that has led some legislative systems (such as in Switzerland, in the states of Oregon and Washington in the USA) to permit assisted suicide and yet outlaw euthanasia. The difference, that the "bystander" merely provides the necessary means for ending life and the person will have to make use of those means him- or herself to end his or life, has led some to claim that assisted suicide is a truly autonomous action, whereas it can not always be ascertained if the choice of euthanasia is really so. Such an approach, it is claimed, speaks in favour of accepting assisted suicide without necessarily accepting euthanasia . Although in theory the distinction between providing the necessary means for a person to end his or her life, and actually ending that person's life through a direct and intentional act, seems quite clear, the boundaries might be more blurred in real life. Writing a prescription for a lethal drug, actually collecting the drug at the

pharmacist, perhaps putting it conveniently at the bed side table, taking off the lid and handing the pills to the patient, and actually placing the pills in the patient's mouth for him or her to actively swallow rather than spit out, all represent forms of providing a necessary means, that has to be followed by some act of the patient in order to end life. And yet they seem to be quite different forms of involvement in terms of active engagement and participation in the patient's own end, some of which apparently come quite close to euthanasia.

8.3 A moral right to assisted suicide

Therefore some of the objections against justifying euthanasia on the basis of autonomy and beneficence also apply to assisted suicide. First, autonomous decisions to receive a certain form of assistance or service (and merely to resist intervention) might be clouded and obscured by the patient's situation of agony, pain and anxiety in cases of assisted suicide as well. Although not impossible, a well-considered autonomous decision not deluded or twisted by the conditions of the situation that produce the request, is indeed hard to ascertain in practice. Those who defend assisted suicide certainly assert that it must be, and in fact can be, restricted to those cases where the wish to receive assistance ensues from a well-considered decision, unimpeded by psychiatric illness or diagnoses. In the Swiss context, this is considered to be ensured through a practice where the assisting person usually explains at length the consequences of drinking the barbiturate for the patient. But there is also criticism of the current practice, including the care and psychological quality of the advice and support for those wanting to commit suicide given by organizations such as EXIT and DIGNITAS.

Secondly, autonomy and autonomous decisions concerning assisted suicide, as well as decisions about euthanasia, are likely to be affected and shaped by contexts of values, views of dignified and worthy life, social and cultural patterns concerning how a seriously ill and dying life might retain or not retain dignity and worth. Requests for assistance in ending life are known to emerge from the patient's assessment of a number of factors he or she considers vital to experiencing quality of life. Only to a limited degree are these factors physical determinants. Other dimensions, such as relational, psychological, existential and spiritual dimensions are likely to be prominent as well. But such factors are susceptible to other forms of response and accompaniment than merely assistance in ending life. Thirdly, as was argued at length in relation to euthanasia (cfr. above) a Christian view of freedom differs from autonomy viewed as self-determination and the sovereign and free planning and governing of one's own life. Its essence is the reception of life as created in the image of God and justified by faith, and on that basis being called to responsible caring for God's gracious gift. Thus, although assisted suicide might, at face value, appear as a more genuinely and undisputedly autonomous action, A Christian notion of freedom can hardly serve as justification for assisted suicide any more than it can euthanasia.

A further consideration sometimes offered by those who defend access to assisted suicide, is that it is less burdensome on doctors than euthanasia. In cases of assisted suicide, the person providing the necessary means (such as lethal drugs to be taken by the patient) can walk away after having done so (not implying that he or she would necessarily do so), as the act of ending life itself is carried out solely by the patient. It frees the doctor of the heavy burden of being the one who carries out the

action which directly ends the patient's life. This might well be the case, but rather than being an argument in favour of assisted suicide, it illustrates the involved degree of abandonment of the person who is ill, suffering, in despair and seeing no way out other than to end his or her life. Compassion and care requires precisely that a person is not abandoned and left alone with the terrible choice of ending or not ending one's life, with the effective means to do so possibly sitting on the bedside table. Although assisted suicide might certainly be conducted in different ways, and might involve the presence of one's loved ones for comfort and accompaniment, the argument that assisted suicide is a more genuinely autonomous action, seems to presuppose that it is carried out in loneliness and entirely by oneself; undisturbed, but also unaccompanied by others. And this can never be what a Christian vision of compassion and care for the ill and dying allows, let alone requires us to do.

Whether or not there could be a moral right to assisted suicide cannot be disconnected from ethical evaluation of suicide as such. Suicide is well known to be in most cases the tragic outcome of psychiatric conditions or diseases such as severe depression, and as such is not primarily an object of ethical or moral judgment. People who attempt to end their own lives or in fact succeed in doing so should not be met with moral evaluation let alone condemnation or attribution of guilt, but rather with care, compassion and comfort, or with grief and regret that adequate help was not provided for them prior to their death. It is, we might say with Bonhoeffer, a marginal situation that does not allow assessment and judgment by others.

That said, there is broad consensus that the Bible and essential elements of the Christian moral tradition, such as the idea of the

inalienable dignity of every human being as the image of God, do not ground or produce a right to suicide. In particular, suicide and the conditions that lead up to it, are not a morally neutral area in the sense that bystanders are free to assist someone in an attempt at suicide. As underlined elsewhere in this text, a Christian view of freedom means responsibility for a life received, not sovereign disposition, self-determination or ownership of that life. If someone out of despair or depression is contemplating suicide, the responsibility of bystanders is not to affirm or approve this decision, but much more to protect life and offer comfort and care to the suffering.

This also applies to evaluations of assistance in suicide. Even if those giving assistance do not themselves bring on death, they are actively supporting the intention of the person concerned to commit suicide, to put an end to his or her life, which in principle is in contradiction to the Christian attitude according to which life is to be preserved and maintained. Our task is in principle to encourage others to live, support them and if possible deter them from suicide. However, no one has the right to condemn someone who because of irreversible deteriorating medical condition and the distress and suffering associated with it can now longer see his or her situation in life as meaningful and no longer has the strength or the will to continue this life.

At the same time, churches should avoid construing these difficult and tragic situations as a choice between being an accomplice in suicide, and abandoning the patient who, after lengthy consultation and evaluation of his or her situation, is determined to go on with his or her choice of suicide. This is particularly challenging in contexts where assisted suicide has been legalised and enjoys with overwhelming support in the population. In such contexts churches cannot simply discharge their responsibility by

condemning a practice. They also have to find ways to be faithful to their calling under circumstances where a large majority of the population supports access to assisted suicide or euthanasia.

Patients who as a well-considered and persistent conscientious choice prepare their suicide, possibly going through excruciating pain, suffering, anxiety, distress and loneliness, should certainly not be abandoned by their Christian community. It is a true expression of the Christian calling to show care and compassion with those who suffer that the deacons, ministers, and volunteers of our congregations continue to be with, accompany and serve the seriously ill and despaired person with the comforting word of God, counselling and prayers, also when he or she has embarked upon a pathway that churches might not see as the ethically ideal and good. Continuing to be with that person should not be ethically dismissed as assisting in someone's suicide, but rather viewed as a token of Christian compassion for a brother or sister who is in a state of deep agony and suffering and can see no other way out.

8.4 A legal right to assisted suicide

No positive right to suicide and assisted suicide can be derived either ethically or legally from the decriminalization of suicide or attempted suicide or from the possible decriminalization of assisted suicide. Thus legal ordinances which make assisted suicide a criminal act do not contravene the European Convention on Human Rights.

The verdict of the European Court of Justice for Human Rights in the case of Diane Pretty in spring 2002 is relevant here. Mrs Pretty wanted the European Court of Justice for Human Rights to ensure that her husband would not be prosecuted if he

assisted her suicide, which in Great Britain is in principle a criminal act. The plaintiff was no longer physically capable of committing suicide because of her illness (amyotrophic lateral sclerosis) and argued that she was discriminated against by comparison with those who could still kill themselves. However, the European Court of Justice for Human Rights ruled that the right to life (Article 2 of the European Convention on Human Rights) and the right to the protection of the private sphere (Article 8 of the European Convention on Human Rights) did not include the right to suicide or killing on request. On the other hand it had to be argued that a benefit was withheld from patients who are no longer in a position to kill themselves.

However, this has made it clear that no positive right to suicide and thus no right to assisted suicide is to be derived from the possible decriminalization of suicide (cfr. above 2.3 for further analysis of legal situation regarding euthanasia and assisted suicide).

8.5 Assisted suicide: conclusion

Like euthanasia, the question of assisted suicide typically arises in tragic situations, where patients are going through terrible suffering and affliction, not only physically, but also psychologically, existentially and spiritually. This tragic context, which might imply that there are moral concerns at stake that can never fully be heeded, should never be ignored.

Assisted suicide is not on a par with euthanasia. The person assisting in the suicide is involved in the death of the patient in a different way, not by intentionally and directly ending someone's life, but by providing the necessary means for the

patient to end his or her own life. In practice, however, the line between the two might not be so clear-cut. We therefore also believe that several of the objections discussed above against euthanasia, pertain to assisted suicide as well. The problems associated with applying autonomy and autonomous decision-making as a reason that allegedly favours euthanasia are the same concerning assisted suicide. Furthermore, although formally an autonomous action in the pure sense of being carried out by the patient him- or herself, it remains a profound problem and challenge that assisted suicide, like euthanasia, tends to involve abandonment of the patient where comfort, companionship and care are called for. At this point it is essential that regardless of any ethical evaluation of this question, churches and congregations within contexts where assisted suicide has been legalised and is regularly performed, not abandon, but continue to accompany, encourage and support the patient, also if the patient's determined choice is to go through with assisted suicide. The serving presence of the congregations' staff and volunteers with counselling, the word of God and prayers, should not be dismissed as complicity in suicide, but much more encouraged as living up to the church's and the Christian's calling.

Recognising how assisted suicide not only involves a component of assisting in the death of another person, but also a component of suicide, requires that the issue of suicide itself is taken into consideration. Recognising how suicide typically results from profound mental affliction and severe depression, moral evaluation is indeed not what is foremost called for. When we are confronted with the issue of assisted suicide it is important to notice how the notion of freedom and responsibility within Christian ethics and a protestant tradition does not involve sovereignty over one's own life in a way that

accepts the choice to end one's life. Also, there is no legal right to commit suicide or a requirement that others should refrain from interrupting an attempted suicide, let alone anything which allows someone to provide the necessary means to do so.

Thus, although there are obvious differences between assisted suicide and euthanasia, these differences are not of a kind which make the objections against euthanasia disappear in relation to assisted suicide. On the contrary, we find that the main arguments against euthanasia presented above apply equally to assisted suicide. A suffering and agonising patient, facing life's end with all the physical, mental, existential and spiritual pain and suffering that might involve, should not be left alone, but much more have the possibility of the accompaniment and comfort of the Christian community to which he or she belongs.

9 Conclusion

The questions of life and death which this document has dealt with touch the deepest concerns of human existence. Patients who wrestle with the acceptance of their difficult situation are fully aware that there is no easy answer. Relatives who see their dear ones suffer are torn between wishing for an end of their suffering through death and hoping for a continued life with them. Doctors who have to make final decisions on life and death feel the burden of this responsibility.

The moral sensitivity called for in these situations confronts us with difficult choices. They cannot be discharged by referring to a given catalogue of moral values with a pre-defined hierarchy of applying such values. They must be met with an empathetic approach as it is shown in the life of Jesus. The Protestant churches in Europe are aware of the many dimensions of moral concerns and judgments in questions of life and death. Such awareness should not be confused with a relativistic or purely situational approach. As this document has shown, human decisions about life and death, thoroughly considered on the basis of biblical tradition and human reason, mirror a clear mandate to celebrate and defend the gift of life by the creator. This includes striving towards an existence in dignity and fulfilment for each person and standing by those who go through grave experiences of suffering. Moral decisions which undermine the respect for life are irreconcilable with Christian faith.

While the decision about the specific way in which such appreciation of life can be fostered must take into account the

specific circumstances of each case, there is an undisputed mandate for Christian faith to engage in the practice of care for each and every human being. Beyond decisions about life and death Christians will do everything to alleviate human suffering and stand by those who wrestle with pain and despair in their last phase of life. Doctors and nurses will make every effort to alleviate pain through palliative care. Relatives and friends will donate their time to be with those affected. Ministers will understand the need to accompany the terminally ill as a central dimension of their ministry.

Caring for people and offering spiritual comfort is an essential part of 'being church'. This includes a clear task of the churches in civil society. They are called to voice protest when legal barriers which protect life are torn down. They are called to publically advocate adequate economic resources in hospitals and hospices to give those struggling with death the best possible care. They have the task to plea for creating an environment in society which fosters a fulfilled life for every member of society including those near to death.

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Many protestant churches have busied themselves in recent years with the ethical questions arising from the medical possibilities for life-extending measures. Particular attention is given here to the question of deciding for oneself on the end of life.

The CPCE Expert Group on Ethics reviewed the position papers coming from the ecumenical context. The resulting aid to orientation was discussed and reworked in February 2011 at a consultation with church leaders, theologians and experts from the fields of medicine, law and hospital pastoral care. The CPCE now presents this result to the public as a protestant contribution to the discussion of a worthy dealing with the end of life. The results achieved so far can offer the basis for a joint protestant way on the European level. The aid to orientation is meant to encourage the churches to work further on addressing the problems in their respective contexts.