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Information, Decision and Self-Determination: Euthanasia as a Case Study

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Abstract

The central notion of this article is that of “decision” as a means to shape one’s life and life biography. Decision is considered to be a prominent feature of contemporary society and the one through which we exercise our autonomy as a right to self-determination. Decisions, however, require information. In contemporary society, information is readily available but the effective use of that information often requires the help of others. Furthermore, as decisions transform into action again we often need others. These “others” must decide for themselves whether to help or assist us as an expression of their autonomy. These concepts of autonomy, decision, information and the other are key notions which we need to understand the role of self-determination in our society. We are accustomed to having legal frameworks which guide, facilitate and limit us in selecting information, making decisions and exercising self-determination. In this article the legal framework of euthanasia, as it exists in the Netherlands, is taken as a case study to illustrate the role of information with respect to the notion self-determination. This article explores how the abundance of information available to us in contemporary society has an impact upon the decisions we make and, more often than not, must make.

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1. “Going Home”

Sol Roth prepared to leave his earthly life. He lay comfortably among white pillows in a special room which had been designed to make the remainder of his life glide by in a peaceful evocation of how the earth once was. Projected on one of the walls were images of the lost beauties of the earth. All was lush and green. Forests appeared and so did flowers in full bloom. Rabbits and deer flitted in and out of view to the music of Beethoven, Tchaikovsky and Grieg. As his end approached so the day projected on the wall came to a close. A dramatic sunset symbolised Sol Roth’s decision to go home. The end of his life was facilitated by the state.

The paragraph above depicts the euthanasia scene in the 1973 cult-classic film *Soylent Green*.¹ This movie tells a story about the state of the earth and humanity after a man-made ecological disaster. Humanity lives in a techno-world gone bad, barren of the natural environment as we know it and also depleted of natural food stuffs (fruit, meat, vegetables, etc.). Food, therefore, is chemically processed and this process monopolised by the Soylent corporation. Life in this apocalyptic vision is solitary, nasty, brutish and, if you so wish, short, since its citizens can opt for state-guided euthanasia. Indeed, the striking feature of this scenario is that in this desperate world the one thing one can control is one’s own death: people can decide to opt out of life and, furthermore, the state will help them to achieve their death wishes.²

The central notion here is that of “decision” as a means to shape one’s life and life biography.³ Decision can be considered to be a prominent feature of contemporary society. Through decisions we exercise our autonomy as a right to self-determination. The ultimate decision would, indeed, be the decision to end one’s life and thereby end one’s autonomy in exercising it. Decisions, however, require information. In contemporary society, information is readily available but the effective use of that information often requires the help of others. Furthermore, as we transform decisions into actions we often need others. These ‘others’ must decide for themselves whether to help or assist us as an expression of their own autonomy. These notions of autonomy, decision, information and the other are key notions to understanding the role of self-determination in our society. It can be argued that the notion of individual self-determination is one of the positive aspects of modern society, based as it is on our notions of the primacy of reason and the emancipation of the individual. A fundamental question, however, is whether the achievements of contemporary society, such as the increasing access to all kinds of information through Internet are a hindrance to the exercise of self-determination or if they facilitate the exercise of self-determination. Self-determination does not imply that anything goes. We are accustomed to having legal frameworks which guide, facilitate and limit us in selecting information, making decisions and exercising self-determination. This is not

¹ *Soylent Green*, MGM, 1973.

² To find out whether this assistance was benevolence based on respect for human dignity or if it had an economically inspired motivation, we advise you to watch the movie for yourselves. It is available on YouTube.

³ It may imply that we take a “decisionist” position holding that we deem all decisions that follow from a valid decision-making procedure as valid. However, we are more concerned with the substantive decision itself, i.e. the decision pertaining to euthanasia rather than the legal procedure that doctors in the Netherlands must follow to determine a request for euthanasia.

to say that our legal frameworks are not subject to change as a result of the exercise of self-determination. Often they are.

In this article, we will use the Dutch legal framework regarding euthanasia as an illustration to help in understanding the role of information with respect to self-determination and how information and the access in contemporary society to the abundance of information. This article explores how the abundance of information available to us in contemporary society has an impact upon the decisions we make and, more often than not, *must* make.

The article commences with an analysis of “information” as a key feature of contemporary society. It is a feature which because of technological innovation has an unprecedented contemporary reach. It pertains, in its essence, to the access to the vast amount of information available on countless Internet sites. This information shapes our individual and social lives. The availability of information and the simple ways of accessing it, influence the way we make decisions and, hence, impacts upon our exercise of self-determination. Although information is abundantly available, it is only channelled through interconnected networks of knowledge. Because of this, we are interdependent actors. We must rely on experts to select and assess the information we need in order to make decisions. However, at the same time, information technology has put our relationship with experts under strain since we can access much information ourselves. This suggests that we have gained some form of autonomy *vis-à-vis* experts, but this is only with respect to access to information and not, or so the argument goes, with respect to its evaluation (knowledge).

The second part of this article, then, sets out the legal framework on euthanasia in the Netherlands. It analyses in particular the role of the doctor, as an expert, with respect to the decision to end life. This analysis shows the extent to which the legal framework relies upon the exchange of information and expert knowledge within the doctor-patient relationship to circumscribe the exercise of self-determination. One reason to explore this point, is to do justice to the autonomy of the doctor. This is not only as an expert but also, and perhaps even more so, as the one who is expected to administer a lethal dose of drugs. This is a discretion which he or she, as a professional, has been delegated to perform by the state through legislation. To clarify: self-determination and euthanasia (or its pendent assisted suicide) involves two parties, each of whom exercises his or her right to self-determination. To deny one of them this right is not to do justice to the true notion of self-determination. It must be made clear at the outset that the Dutch *legal* framework on euthanasia does not take self-determination as an explicit point of departure which is expressed in a legal right to euthanasia. Rather, the legal framework focuses upon the doctor’s actions *ex post facto*, from a criminal perspective and “ignores”, so to speak, the patient. Information and the expert evaluation of this information prove to be fundamental for the decision to end life, and the subsequent action, therefore, is not unlawful. The legal framework makes clear that a doctor can lawfully end life if the decision to end life is based on a proper, expert evaluation of (medical) information. Only then can the dialogue within the doctor-patient relationship arrive at a course of action which will end the life of the patient lawfully. Recent developments suggest that there is a desire to emancipate decisions which pertain to the end of life from expert and objective evaluation. These developments are discussed in the concluding part of this article and refer on one side to the idea of non-clinical *existential* suffering and on another to the problem of free will with respect of Alzheimer patients in particular.

2. Information and Decision

It is common practice to describe modern society as having one essential aspect. This aspect usually either identifies a problem or highlights a particular prominent achievement in modern society. Hence, “risk society” is the descriptive phrase used by Ulrich Beck to denote an essential, unprecedented problem of modern society, namely its confrontation with risks which are the side effects of modernity’s successes.⁴ Similarly Bauman refers to “liquid society”.⁵ Liquidity is here a feature to juxtapose with the apparently solid society, represented by steel and concrete, and set rules and traditions. Other perhaps less abstract identifiers of modern society refer to the “information society”,⁶ “prevention society”,⁷ “multicultural society”,⁸ and so on. All these denotations highlight specific features which, according to the theorist in question, frame the essence of contemporary society. In this article, we focus on the notions of decision and information since these are pivotal to the notion of self-determination. To be sure, we do not seek to offer a fully elaborated theory of society in terms of decision and information. We merely seek to describe that part of the societal context which contributes (or not) to the exercise of self-determination.

2.1. Problems of Information

We characterise contemporary society in this article as a society in which evolution revolves around the notion of information. We are not concerned with the particular content of information, at least not primarily. Rather, we are concerned with how technology facilitates the dissemination of and access to information in such abundance and the new questions, of various kinds, this poses.⁹ These questions are encapsulated in the idea of “manufactured uncertainty” as noted by, among others, Slevin.¹⁰ To put it more concretely: much as the invention of the printing press caused a fundamental shift in information provision in the fifteenth century,¹¹ the invention and application of ICT (internet, email, etc.) has caused a similar shift in information provision.¹² Our focus here is on the consequences of the use of new information

⁴ U Beck, *Risikogesellschaft – Auf dem Weg in eine andere Moderne* (Frankfurt am Main: Suhrkamp, 1986).

⁵ Z Bauman, *Liquid Modernity* (Cambridge: Polity Press, 2000).

⁶ The terms information or knowledge society as descriptors of society are used by, for example, Lyotard. See [J-F Lyotard](#), *The Postmodern Condition* (Manchester: Manchester University Press, 1984).

⁷ H Boutellier, *De Veiligheidsutopie* (Den Haag: Boom Juridische Uitgevers, 2003).

⁸ This is a popular description in the Netherlands. See W Shadid, *De Multiculturele samenleving in Crisis – Essays over het Integratiedebat in Nederland* (Heerhugowaard: Gigaboek, 2008).

⁹ See also: [C Fuchs](#), *Internet and Society: Social Theory in the Information Age* (New York: Routledge, 2008); J Slevin *The Internet and Society* (Cambridge: Polity, 2000).

¹⁰ Slevin, note 9 above, at 13. See also, A Giddens, *Beyond Left and Right: Future of Radical Politics* (London: Blackwell, 1994).

¹¹ J A Dewar, *The Information Age and the Printing Press: Looking Backward to See Ahead* (Rand, 1998).

¹² See D Baecker, *Studien zur nächsten Gesellschaft* (Frankfurt am Main: Suhrkamp, 2007); P Drucker *Managing in the Next Society* (New York: Truman Talley Books, 2002).

technologies which concern the digitalisation of communication and dissemination of information on a global scale on the ways we shape our lives.

An important question about this involves concerns about how to deal with the abundant availability of information. This question breaks down in various interrelated sub-questions.

One of these questions refers to the quantitative aspect of information and the problem of selection that follows from it. What we mean is that there is an unlimited access to information on virtually any topic. Put any topic into Google and the result list amounts to, more often than not, hundreds of “hits” if not thousands.¹³ The point here is that efficiently accessing information requires using a particular strategy: when seeking information we need to know beforehand why we need the information and what the sources are we can “trust”. Having such a strategy makes it possible for us to select relevant information.

Another question refers to the problem of interpretation. Even when we have access to information, say medical information, it does not automatically mean that we understand this information, even when it is presented to us in layman’s terms, if we are not trained as doctors. The same goes for legal information, scientific information or any type of information which demands expertise in providing and understanding it. Although new technologies have democratised access to information, they have not ensured the democratisation of knowledge which is understood as the proper evaluation and interpretation of data. In many instances we need experts in order to make good use of information. Information gathering in our society has acquired its quantitative aspect through the digitalisation of information but this has not (yet) guaranteed a qualitative evaluation.

Yet another question pertains to the sources of information.¹⁴ These sources are often invisible or, at least, anonymous. This fact could render information meaningless, as information acquires meaning when put in or asked from the proper context. For example, in the City of Utrecht preparations are being made to celebrate the “Vrede van Utrecht”.¹⁵ Will websites focus on the event as bringing peace to Europe through diplomacy (rather than war) or will they refer to the treaty of Utrecht as a regulator of the slave trade? The point is that information accessed digitally is often stripped of its own context if the person accessing the information is unable to trace the source of the information and is unable to evaluate the source. With respect to medical information, it may well be that that information is not scientifically “neutral”. It can be the case that the information is accurate but is influenced by its provider. An

¹³ As an example for this article, searching for “euthanasia” as a key word resulted in 3,740,000 hits (accessed 15 April 2009).

¹⁴ Baecker, see note 12 above, at 17-18: “Er [the PC and hence the Internet, BdV/LF] konfrontiert mit Kommunikationen, von denen wir nicht wissen, wer sie wo und wie zustande gebracht hat. Zahlen und Texte rollen über den Bildschirm, die wir einschätzen müssen, ohne eine verlässliche Auskunft über ihre Quelle und ihre Absicht zu haben. Die einzige Entscheidung, die wir angesichts der auf der Computerschirm auftauchenden [...] Informationentreffen können, lautet ob wir mit dieser Information hier und jetzt etwas anfangen können oder nicht”.

¹⁵ Google result, 369,000 hits (accessed 15 April 2009).

example of this would be a pharmaceutical organisation or an organisation that has a particular moral conviction giving information about euthanasia.¹⁶

It is clear that information is abundantly available and easily accessible. The problems lie with selecting the “right” information, interpreting and evaluating it and with the reliability of the information (source reliability). These are interrelated problems and they cannot be avoided: as autonomous individuals we must learn to deal with information. Indeed, it is exactly because we are *autonomous* individuals that we must deal with information in order to make the decisions which shape our daily life.

2.2. Self-determination: the necessity to decide

Contemporary society offers abundant sources of information. Information is for making decisions. Society requires us to make decisions on a daily basis. These range from trivial matters such as the daily shopping and aesthetic life style options to more fundamental choices about the form and contents of our intimate relations and the beginnings and ends of life. Trivial choices are, most of the time, rather unproblematic and rarely require an appeal to fundamental beliefs, convictions or values. These decisions might be guided by aesthetic preferences, pragmatic or practical considerations or by force of habit. In this article, we are however concerned with the fundamental and demanding decisions that pertain to the quality of our lives, such as decisions concerning the end of life.

Indeed, contemporary society confronts us with the necessity of making decisions and this necessity follows from the typical, historically determined state of affairs of modern society. This – the need for information – may seem self-evident but is, at least in the view of the authors, a feature of modern society which is philosophically underpinned by the concept of reason as well as liberal theory. Thus, the necessity of decision making concurs with the individual liberties we enjoy in contemporary society. At the core of these liberties lies the notion of individual autonomy: the idea that we are the masters of our own lives. This idea is the result of what are termed the processes of modernisation, in particular the processes of individualisation and secularisation.

Liberalism depends on the ability of an autonomous individual to make rational decisions about his or her own life. This rationalism provides the core assumption about our relationship with the state. Indeed, it is worked out in a myriad of civil-political rights which have been laid down in international treaties and in national documents, such as bills of rights, constitutions and ordinary legislation. All of these instruments have emphasised the importance of individual self-determination and the limited role of the state which stays away from interference with the private sphere of the individual or, if necessary, demanding action from the state to guarantee the exercise of self-determination. This latter aspect has gained momentum with the introduction of socio-economic rights demanding a positive obligation on the part of the state to ensure the proper exercise of fundamental rights. This legal development can be seen in ideas about human rights which seems to function as the latest ideology

¹⁶ Information provided by the Dutch Association of Voluntary Euthanasia would differ essentially from that of the pro-life movement. (In this example, the sources are known, univocal and traceable, but this may not always be the case.)

of Western modernity. Furthermore, the protection of self-determination is perceived as the global legal-normative core of our society.¹⁷

2.3. The autonomy to decide

Developments which allowed the creation of the *autonomous* individual may be seen in, among others, the process of secularisation. We understand this as the secularisation of the public space as well as “the falling off of religious beliefs and practices”, emancipating the individual from tradition and religion and emancipating him and her from prescriptions about how to live his or her life.¹⁸ Indeed, in the context of this article, the secularisation of public space allows us to start looking differently at issues surrounding life and death. Medical developments have strengthened this. They have helped in changing our view on life (in respect of its duration, quality and so on) and they have taken life out of the hands of God. Birth control, abortion, self-determination, bodily integrity and informed consent (as a lego-normative cornerstone of medical treatment) allowed us to control decisions about the beginning and end of life. Indeed, possibilities to extend life (or to have it ended, for that matter) and to improve life’s quality have become core business of medical and pharmaceutical services and increase day-by-day. All this seems to facilitate a shift from the belief that the beginning and end of life is the domain of a God to the idea that it is or at least can be the domain of human decision-making. It signifies the ‘material’ side of the principle of self-determination with law being the formal aspect which enables the material manifestation of self-determination.¹⁹

* * *

The argument so far goes as follows: self-determination implies making decisions. Indeed, it suggests that self-determination necessitates decision making. Individual liberty, as the philosophical underpinning of the autonomous modern individual, can be interpreted as the freedom to choose among the available options to shape one’s life.²⁰ This freedom implies the necessity of making decisions. We make these decisions on the basis of information. Problem exist in the correlation of the abundance of information, its interpretation and evaluation, the necessity to make decisions and the need to seek guidance to make the “right” decisions based on the “right” information. When we consider decisions pertaining to the end of life as the ultimate expression of self-determination, we do not suggest that there exists a necessity to decide about euthanasia. Rather, we suggest that contemporary society confronts us with situations in which we are forced, as autonomous individuals, to think about our life’s end when we are ill or when we consider our quality of life to be

¹⁷ See, for a critical analysis of the (ideological) function of human rights, C Douzinas, *Human Rights and Empire* (Abingdon: Routledge-Cavendish, 2007).

¹⁸ Conform. C Taylor, *A Secular Age* (Harvard: The Belknap Press). (We agree less with Taylor’s third meaning of secularisation, i.e. religion as an option. We consider it rather a result of the process of secularisation.)

¹⁹ This shift is also visible with the introduction of the quality of life doctrine in medico-ethical theory as the counter weight of the long-prevailing sanctity of life doctrine. See P Lewis, *Assisted Suicide and Legal Change* (Oxford: Oxford University Press, 2007).

²⁰ It causes Ulrich Beck to speak of “forced individualisation”. See U Beck and E Grande, *Das kosmopolitische Europa* (Frankfurt am Main: Suhrkamp, 2004) at 50.

affected by illness, pain and suffering. This process of thought is fed with information exchanged in a dialogue with one's doctor and, indeed, it could lead to a conclusion leading to a course of action that ends one's life. It is this particular aspect that we deem to be a central feature in the legal framework of euthanasia in the Netherlands and is the subject of analysis in the next part of this article.

3. The Dutch Legal Framework²¹

Even though there are international legal frameworks which span the world and attempt to ensure the right to individual self-determination,²² we see that within the nation state, self-determination is circumscribed in many different ways and with respect to many different aspects of an individual life. Indeed, when it comes to the issue of lawful euthanasia, we can observe that most national legal frameworks exclude euthanasia as an option or object of self-determination. The Dutch answer, however, is different. Its framework, which allows for lawful euthanasia, was the culmination of legal entrepreneurship, social debate, medical lobbying and a suitable political climate.²³

3.1. The Euthanasia Act, 2001

Legislation pertaining to lawful euthanasia and assisted suicide was introduced in 2001. The shorthand reference is the *Euthanasia Act 2001* but its official name is the *Termination of Life upon Request and Assisted Suicide (Review Procedure) Act 2001*. The Act amends ss 293 and 294 of the Dutch Criminal Code. Section 293 makes it a criminal offence to intentionally end the life of another upon his or her express and sincere request. Subsection 2 of s 294 makes it a criminal offence intentionally to assist another in his or her suicide or to provide the means to do so.²⁴ Both sections imply that the person seeking death is a person of sound mind; the sections do not cover actions pertaining to the withdrawal of treatment, passive euthanasia or involuntary euthanasia.²⁵

²¹ This paragraph, and the next, draws to a large extent on previous research, published, among others, in: U de Vries, "Dutch Perspective; The Limits of Lawful Euthanasia" (2004) 13/2 *Annals of Health Law* 365-392. It goes without saying that there is a vast amount of literature on Dutch euthanasia law which has appeared in many different jurisdictions and in many languages. English language texts include texts by the research group of John Griffiths, such as: J Griffiths, A Bood and H Weyers, *Euthanasia and Law in the Netherlands* (Amsterdam: Amsterdam University Press, 1998) and J Griffiths, H Weyers and M Adams, *Euthanasia and Law in Europe: With Special Reference to the Netherlands and Belgium* (London: Hart Publishing, 2008). Other relevant texts include: P Lewis, *Assisted Suicide and Legal Change* (Oxford: Oxford University Press, 2007). For a more general discussion on some of the topics surrounding euthanasia, the list of articles would be nearly endless. Where relevant, references are made within the text below.

²² Such as the *European Convention of Human Rights and Fundamental Freedoms 1956* and the *International Covenant on Civil and Political Rights 1976*, which are based on the *UN Declaration of Human Rights 1948*.

²³ See also J Kennedy, *Een Weloverwogen Dood – Euthanasie in Nederland* [A well-considered death – euthanasia in the Netherlands] (Amsterdam; Bert Bakker, 2002).

²⁴ Subsection 1 of s 284 makes it a criminal offence to intentionally compel another to commit suicide.

²⁵ These courses of action pose different legal and moral questions that must be addressed elsewhere.

The two offences are similar in what they seek to protect: life and the value we ordinarily attach to life.²⁶ They fundamentally differ in the action which is criminalised (*actus reus*). Euthanasia is the intentional killing of another – an action which leads directly to someone's death – upon that person's request. Assisted suicide leaves the action of killing to the person who seeks death. The other person involved provides the means or otherwise assists. He or she does not kill the person but rather allows him or her to die. This fundamental difference has been of little concern in Dutch case law or legislation. One reason for this may be that case law is more concerned with addressing the motivation behind the course of action which leads to ending the life of a person with a sincere death wish (e.g. to end the suffering).

In any event, the 2001 Act amends ss 283 and 284, allowing a doctor to end a patient's life when certain conditions are met. This is important to stress: the Act allows *doctors* to end a life if certain conditions are met.²⁷ In effect the Act allows for a medical exception when a doctor is confronted with a death wish of his or her patient and the doctor is convinced that (i) the death wish is made in earnest, i.e. is sincere and voluntary and (ii) flows from a condition of hopeless and unbearable suffering. Furthermore, the doctor has (iii) consulted the patient about the prospects and situation and both have come to (iv) the conclusion that no alternatives are realistically available. As a matter of course (v) the patient must have been seen by at least one other doctor, expressing his opinion in respect of the first four criteria.²⁸ If these conditions are met the doctor may act upon the request either through euthanasia or in assisting in the suicide, providing, for example, a lethal dose of drugs. The doctor must do so (vi) with all due care. The doctor must inform the local coroner of the course of action, pertaining to death by unnatural causes.²⁹ Furthermore, the Act provides in s 3 for regionally based euthanasia review commissions whose task it is to determine the doctor's actions *ex post facto*. If such a committee were to deem the doctor's action as not in line with the criteria, it would inform the prosecution (s 9), who could take action at its discretion.³⁰

²⁶ The sanctity of life doctrine is but one expression of this value and should not be equated with it.

²⁷ A doctor is anyone who is registered as such under the relevant legislation, i.e. Wet BIG (*Professions Individual Health Care Act 1993*).

²⁸ This doctor does not necessarily need to concur with the opinion of the first doctor.

²⁹ Wet op de lijkbezorging, § 7(2), 1991 (Stb 2001, 194) [*Burial Act 1991*]. The doctor is required to notify the local coroner, fill in a form, and provide details about the act and the manner in which he has adhered to the due care criteria. The form is specified by law. See *Vaststellingsbesluit formulieren bedoeld in de Wet op de lijkbezorging betreffende overlijden ten gevolge van niet-natuurlijke oorzaak* (No. 5133202/01/6 –6 Mar. 2002) [Decision to determine use of forms as meant in the Burial Act with respect to death by unnatural causes].

³⁰ It is outside the scope of this article to analyse this aspect in more detail. Data suggest that doctors are unwilling to report due to the degree of uncertainty as to the possibility of criminal prosecution and also because they believed they did not carry out a life-terminating procedure. However, the *2007 Annual Report* of the Regional euthanasia review commissions reported an increase in reported cases from 54% in 2001 to 80% in 2007. See http://www.euthanasiecommissie.nl/Images/Jaarverslag%202007%20Engelse%20versie_tcm21-11566.pdf (accessed 10 March 2009).

3.2. Case law: necessity and professional knowledge

Looking at the Act in isolation, it seems as if the legislation allows for euthanasia in discrete cases. Although there has been intense legislation and societal and professional debate,³¹ in the end the legislation is the codification of two key decisions of the Dutch Supreme Court.³² These decisions pertain to an interpretation of the so-called necessity defence, relied upon by prosecuted doctors in court. It is in this interpretation that we see the importance of professional knowledge and expertise as a determinant of self-determination which in effect limits the scope of self-determination for both doctor and patient.

The Dutch necessity defence is broader than the one which exists in English common law.³³ It arises when the accused was under some physical or psychological constraint or duress which would violate the law. The constraint or duress in such cases is of such an extent that the accused could not but give in and violate the law. Thus, a man who is forced to give up a bag of money, he holds in trust for another, at gunpoint can do so justifiably. This is what necessity ordinarily means in common law.³⁴ Under Dutch law, necessity can also arise in the absence of an external pressure. In such a situation the accused has made a conscious decision (as an expression of self-determination) to violate the law. He or she makes such a decision when confronted with a conflict of duties: the duty not to violate the law and another duty in which he or she considers it to be worth breaking the law so as to achieve a greater good. The decision is justified if the means used was proportionate to the aim (the greater good) and there were no other less radical means to achieve this aim.³⁵

How does this apply to euthanasia and assisted suicide? This was addressed in earnest in 1984, in *Euthanasie I*.³⁶ In this case, a doctor was presented with the death wish of a 95-year-old patient. Her wish to die stemmed from her unbearable and hopeless suffering, caused by an underlying clinical condition. As far as she was concerned her suffering could only be relieved if she was allowed to die in a humane manner. The doctor agreed to the request, administering a lethal dose of drugs. He was prosecuted. In his submissions to the court, the doctor relied on the defence of necessity, arguing that the patient's death wish had confronted him with (i) a conflict between his legal duty to preserve life (as implied under s 293) and (ii) his professional duty to relieve

³¹ Reported in, among others, Kennedy, note 24 above; Griffith, Bood & Weyers, note 21 above, at chs 2 and 4.

³² HR 14 November 1984, NJ 1985, 106 (*Euthanasie I*) and HR 21 Oktober 1986, NJ 1987, 607 (*Euthanasie II*).

³³ U de Vries (2004), see note 21 above, at 497-498.

³⁴ It may even be extended to cases "where it is excusable in an emergency to break the law if compliance would impose an intolerable burden on the accused", *ex Perka v R*, [1984], 1 DLR (4th) 12, *per* Dickson J.

³⁵ Thus, an optician who sold a pair of glasses after closing time to a person who had lost his and was completely helpless made a justifiable choice between his legal duty to observe opening hours and his professional duty to aid his clients (*ex* HR 16 oktober 193, NJ1932, 1329 (*Optician*). It may well be that common law necessity may extend to a conflict of duties but not as a plea to answer a charge of homicide: *R v Dudley and Stevens*, [1884] 14 QBD 273.

³⁶ HR 14 November 1984, NJ 1985, 106. In the Dutch jurisdiction it is common for court reporters to provide some Supreme Court cases with a "nickname" in addition to their publication details instead of using the names of the parties.

his patient's suffering. To discharge of his professional duty he had to fulfil his patient's death wish, thus breaching his first duty and thereby committing a crime. As we have seen, the choice would be justified if the means used was proportionate to the aim (to fulfil the patient's death wish) and if there was no alternative less radical means to relieve the patient's suffering. This depended on the circumstances of the case. Considering these, the court accepted the doctor's diagnosis and his assessment of the patient's suffering as being hopeless and unbearable. It also accepted the doctor's conclusion that no other alternative treatment options were available to relieve the patient's suffering, which would not result in the patient's death. Furthermore, the court accepted the doctor's conclusion that the patient's death wish had been voluntary, sincere and persistent. In other words, the patient had understood and accepted the only real option available to her. (It could be argued that the death wish lay in the consent to the available option open to her.) To this end, the doctor had consulted his assistant and had come to his conclusions by reference to current medical ethics and his medical skill and knowledge. In doing so, the court decided he had made a justifiable choice to break the law and achieve a greater good: to fulfil the patient's death wish. With this judgement, the court cleared the way for lawful euthanasia.

3.3. Professional expertise and common practice

Case law and legislation have recognised, overtly, what is really a matter of common medical practice. Conscientious doctors regard the alleviation of suffering as one of their primary medical objectives and at some stages of acute suffering life should not be artificially continued but could be ended intentionally upon request. Recognising this amounts to an express rejection of the "double effect" doctrine.³⁷

What makes doctors qualified to determine the adequacy of the patient's request, in particular with respect to the patient's suffering? In other words, why is euthanasia "medicalised"? One reason is that this "medicalisation" allows for an objective evaluation of the request to die. This evaluation is based upon the circumstances of the case; circumstances that can be placed against the background of medical knowledge. Indeed, the courts, in their case law, did not consider whether the patient's suffering was endless and hopeless but rather whether a doctor could have come to this conclusion. And, the doctor could come to this conclusion if and when, at least, the suffering was based upon or flowed from a clinical condition. Indeed, the nature and the extent of the suffering as well as the nature of the underlying clinical cause inform the doctor about the proportionality of the proper course of action and available alternatives. In most cases the underlying condition has caused patients to have entered a "dying" or "terminal phase".³⁸ Death was eminent and euthanasia

³⁷ It represents the position that the administration of medication is intended to relieve suffering but recognises, as an unwanted side effect, the acceleration of death. It now has reappeared under the heading of "terminal sedation". The "advantage" is that death is deemed natural and, hence, the coroner need not be informed. For detailed analysis of the so-called "double effect doctrine" pertaining to end-of-life decisions, see for example, D Tomkin and P Hanafin, *Irish Medical Law* (Dublin: The Round Hall Press, 1995), which cites at 87 J Glover *Causing Death and Savings Lives* (Harmondsworth: Penguin, 1977).

³⁸ Recent statistics over 2007 show that in the majority of all reported cases of euthanasia, the underlying illness was physical, in particular cancer (1768 out of 2120 reported cases); see Regional euthanasia review committees, 2007 Annual Report, online:

anticipated death. It allows for an evaluation of the patient's suffering based on objective information and regardless the nature of the underlying clinical condition. Indeed, the Royal Dutch Medical Association argued that it is irrelevant whether suffering stems from a terminal illness or a psychological condition. It would insufficiently recognise the importance of how the suffering is experienced by patients so long this suffering could be objectively determined. This position was adopted by the Supreme Court in the *Chabot* case, which we discuss below.

4. Self-Determination Entrenched

Medical information acts as a cornerstone for the legal framework, allowing patients and doctors to decide on the proper courses of action, including one which can lead to killing the patient. Thus, information is crucial to the exercise of self-determination. At the same time, information is crucial in limiting the exercise of self-determination. Although, one may have a death wish, Dutch law has not recognised a system of euthanasia on demand or a right to euthanasia emanating from the right to self-determination.³⁹ It is the nature of one's medical condition and the suffering that follows from it, which is, by reference to medical knowledge and expertise, evaluated and conditional to one's autonomy to have life ended.⁴⁰ This interlocutory conclusion anticipates upon the analysis of further case law. The first case illustrates the importance of medical knowledge as a means to circumscribe self-determination, both by the patient who seeks death and the doctor who seeks to assist. The second case illustrates how self-determination is entrenched when there is, what can be termed, an "informational void", in particular when there is no objective information upon which a decisions to end life can be based.

4.1. Clinical suffering: Chabot

The history of the patient, Netty, is so tragic, so appalling that it would require a Bronte or Dostoyevsky to do it full justice. She was presented in 1991. Dr. Chabot diagnosed depression without psychotic symptoms. The depression was a result of a complicated mourning process. Netty had married when she was 23. The marriage was unhappy. Two children were born. In 1986 her eldest son committed suicide. This affected her deeply, marital problems worsened. She started to express a death wish. However, she promised herself that she would not attempt suicide until her youngest son was able to fend for himself. Meanwhile she underwent psychiatric treatment. She felt that this was of no help though. In 1988 Netty's father died. She left her husband and divorced him in 1990. In that year her younger son was involved in

http://www.euthanasiecommissie.nl/Images/Jaarverslag%202007%20Engelse%20versie_tcm9-24918.pdf (accessed 10 March 2009).

³⁹ A position pointed out in a previous publication; see: U de Vries, "Can a legal Right to Euthanasia Exist? A Dutch Perspective on a Universal Medico-Ethical Dilemma" (2003) 8/2 *Medico-Legal Journal of Ireland* 24-35.

⁴⁰ The UK *Abortion Act 1967* seems to express a similar sentiment: the decision pertaining to abortion is based on clinical consideration before the abortion itself can be considered legal.

a serious road traffic accident. While he was in hospital, doctors discovered a malignant tumour in his brain. He died in 1991. On the eve of his death, Netty had bought four graves – two for her two sons, one for herself and another for her ex-husband. She planned to be buried between her two sons. Hours after her youngest son died, she attempted suicide. From then on she became totally preoccupied into her own death. However, she also wanted to die in a humane manner. Eventually she came into contact with Dr. Chabot, via the Dutch Society for Voluntary Euthanasia.⁴¹

Presenting this case in such a compelling way may sway many to support the brave decision Netty made. Others may consider the compellingness of the story as an illustration of a dangerous slippery slope, where mere depression and suicidal tendencies can lead to the suggestion of a doctor who says: “I, your doctor, wash my hands and give you whatever you like” – euthanasia on demand. But this is not the case. The Dutch Supreme Court had already made it quite clear in *Euthanasie I* and *Euthanasie II* that any course of action leading towards euthanasia or assisted suicide demands a careful and medical analysis of the suffering upon which the death wish is based.

However, in these cases, and indeed in most cases a death wish is based on a physical illness, in particular many types of cancer.⁴² Here the hopelessness of the illness as well as the hopelessness and endlessness of the suffering can more readily be determined objectively by reference to medical knowledge and expertise. But it is the suffering that is the determinant. This was recognised by the Supreme Court in *Chabot* which rejected the idea that euthanasia should be limited to particular causes of suffering. It did hold, however, that in the absence of a physical, terminal illness a more careful analysis was warranted. Had Dr. Chabot conducted such an analysis? The Dutch Supreme Court held he did in respect of his determination of the suffering.

Chabot had diagnosed Netty as suffering from a depression *without* psychotic symptoms. This was the cause of the suffering – a clinical cause recognised as such medically and listed in DSM III R (the Diagnostics Statistical Manual as drafted by the American Psychiatry Association and employed worldwide as a standard for diagnostic practice). Having established the cause of the suffering, Dr. Chabot had evaluated the hopelessness and endlessness of the suffering itself. The court accepted that Dr. Chabot had conducted a careful analysis. It accepted the evidence that the doctor was confronted with a voluntary and persistent death wish from a competent person whose suffering was hopeless and unbearable. This situation confronted him with the question whether to fulfil the death wish of the patient or to refuse his assistance and to maintain the life of the patient. All experts in court agreed that at all times the accused had balanced these duties with due care and by reference to current medical ethics and practice.

Eventually, Dr. Chabot was found guilty, as he had failed to have consulted another doctor who had seen Netty but the court imposed no sentence as a matter of judicial

⁴¹ U de Vries (2004), see note 21 above, at 496.

⁴² See note 38, above.

discretion.⁴³ The importance of the decision is in that the Supreme Court affirmed the role and function of professional autonomy. It confirmed and emphasised that the defence of necessity is to be determined by reference to medical judgment alone. It ruled, in fact, on the lawful boundaries of the doctor-patient relationship and recognised the value of medical knowledge. In a way, the court also recognised that the patient's own perceptions of the nature and extent of her illness required to be taken seriously. Indeed, as suggested in an earlier article, the case could be taken at one level as a suggestion that the patient was sufficiently *compos mentis* to formulate her death wish, and that this wish should be respected. On another level, however, it could be suggested that the patient displayed a sufficient capacity to consent to the sort of palliative treatment that actually ended her life. It is in this latter aspect that the boundary is drawn and is reiterated in the next case which deals with non-clinical existential suffering.⁴⁴

4.2. Existential suffering: Brongersma

This case concerned an older man who was essentially tired of life. He had no illness except for the small illnesses and inconveniences which come with old age. He had been consulting his doctor since 1986 about his state, which was causing him to suffer hopelessly and endlessly; he longed to die and attempted suicide in 1996. More and more he suffered under his physical deterioration and "existential" suffering.⁴⁵ Mr. Brongersma and his doctor discussed his desire to die and the possibility of assisted suicide in more detail during eight subsequent interviews. In addition, a psychiatrist diagnosed Mr. Brongersma and concluded that he did not suffer from any psychiatric illness which might explain his desire to die. Another doctor confirmed that Mr. Brongersma's desire to die was sincere and voluntary. In April 1998, Mr. Brongersma committed suicide assisted by his doctor.

This case poses a question about whether non-medical euthanasia could be allowed. The trial court considered that suffering of this type is exclusively subjective and consists of both situational and personal elements. That there could be no *objective* evaluation of the information was implicit in the opinions of the experts instructed by the court to report on the case. As they could not rely on a clinical cause the experts considered whether the suffering was "real" instead and that this consideration depends on the character of the patient, his personality and integrity.⁴⁶ Since the experts' conclusion was that a person can suffer without illness, the trial court concluded that the doctor could justifiably rely on the necessity defence in such a circumstance. This position was rejected by the Supreme Court on final appeal in 2002.⁴⁷

⁴³ Conform art 9a of the Dutch Criminal Code. (Note: The case was heard prior to the *Euthanasia Act* coming into force but after the criteria for euthanasia were settled by the court in 1984. The point of concern for this article is his determination of suffering.) See U de Vries (2004), see note 21 above.

⁴⁴ U de Vries (2004), see note 21 above, at 506.

⁴⁵ Defined by one of the experts at the trial stage as the unbearable suffering of life in the absence of any clinical cause and without hope of any improvement. See R. Haarlem, 30 October 2000 (LJN AD7926), at 5.

⁴⁶ R. Haarlem, 30 October 2000 (LJN AD7926), at 5 (decision of the District Court in Haarlem).

⁴⁷ HR 24 December 2002, LJN-AE8772 (decision of the Dutch Supreme Court).

Essentially, the Supreme Court held that in such cases the doctor could place himself outside of the medical realm since the determination and evaluation of the patient's suffering is not medically based (allowing for an objective determination). Life problems are not medical problems: the doctor is not a specialist on questions concerning existence such as, for example, hopeless despair, loneliness, or existential suffering caused by the inability to adapt to a new situation. The court adopted the opinions of the experts who were appointed by the Court of Appeal. They held that no consensus existed among doctors as to whether duty existed to aid people with death wishes based existential suffering. It may well be that Brongersma's doctor was right in what he did, but it cannot be demanded from all doctors as part of their professional practice. Requests could only be honoured if the suffering is derived from a psychological or physical cause. Indeed, the experts agreed that lawful euthanasia should be restricted to cases that are medically indicated.

4.3. Professional autonomy en self-determination

The case shows that at least from a legal perspective, self-determination by the patient is limited by the *professional* autonomy of the doctor, who, based on his skill and technological knowledge makes a considered evaluation about the request to die. There is a distinction between self-determination and professional autonomy. The former refers, at least in the context of this article, to the self in terms of our individuality, whereas the latter implies the way in which autonomy is attached to the professional, functional roles in our society. The court has been quite clear that this professional autonomy entrenches the personal autonomy of a doctor: the doctor cannot consider a request other than in clinical terms and any doctor who does not want to entertain the request in the first place (as an expression of personal autonomy) is allowed to refer patients elsewhere as a matter of professional conduct.

Information is the key feature and consists, in the context of euthanasia, of information pertaining to the health or illness of the patient and his or her suffering; it is information of a particular kind: medical information which is obtained through diagnosis and developments in health care science. The combination of factual information about the patient's health and scientific information enables doctors to evaluate the patient's request to determine its validity. Within the doctor-patient relationship, subsequently, alternative courses of action may be discussed, where the doctor translates or interprets the medical information for the benefit of the patient, solving, as it were, the three problems relating to the access to abundant information. The consent to a particular course of action, then, is perhaps the expression of the patient's self-determination.

The Brongersma case shows, in effect, the existence of an informational void. The decision to end life was made in the absence of any medically relevant information. Rather, it may be suggested, the decision to end life here pertained to information of a different kind, perhaps more philosophical or spiritual but at least information which cannot be evaluated in objective terms to legitimise the doctor's actions. Consequently, it could not be considered to be an expression of professional autonomy. It remained a value judgement and in this sense a true expression of self-determination with related to the man's *quality* of life. Indeed, it may well be that in

the future the discussion about euthanasia will focus on this aspect more and more,⁴⁸ rather than upon information which can be objectively evaluated, as in the following scenario: there is a medically recognised illness, which provokes hopeless and endless suffering that can be measured in objective terms, which would justify euthanasia or assisted suicide if the patient so requests.

5. Concluding remarks: self-determination, free will and information

So far, we have always presumed that autonomous decision-making is a manifestation of free will. The above discussion has shown that making decisions in situations where free will is not at stake or put into question are difficult and surrounded by all kinds of ethical questions. But, what if free will is under siege and put into question or, at least, it is a matter of time that autonomous decision-making about one's life's end is no longer an option? This issue is now one of the issues in the ongoing debate about euthanasia and was raised in respect of patients suffering from Alzheimer's Disease who express a sincere wish to prevent entering into a state of complete oblivion and the loss of (perceived) dignity attached to it.

The general information about Alzheimer's gives people diagnosed with the disease pretty good idea about how their lives will become. It consists, in short, of a persistent deterioration of faculties, in particular cognitive faculties. The disease is progressive and fatal. It destroys brain cells and it causes problems with memory, thinking and general behaviour, to the extent that it affects work, lifelong hobbies or social life.⁴⁹ For some patients it might also imply a loss of dignity which makes life not worth living and some of these patients may seek to control their own death by requesting euthanasia.⁵⁰ This state of deterioration could be considered as a state of hopeless and unbearable suffering. This information is widely and easily available and can be used by patients to make a sincere and persistent decision to request euthanasia or not. The same applies for doctors who, on the basis of this information, can make a professional decision to cooperate or facilitate the patient's death wish or otherwise. These are difficult decisions but in terms of information, not impossible.

The matter becomes, however, more complicated as information reporting on new technological-medical developments becomes available. This new information comes across as causing the defragmentation of existing information and calls, again and again, for a re-evaluation of all available information. This re-evaluation, subsequently, can put in doubt decisions made previously. As a way of illustration, and only that, clinical trials have recently shown that a particular medicine that is prescribed to patients suffering from rheumatism or psoriasis has a direct and immediate positive effect upon the cognitive faculties of patients suffering from

⁴⁸ A report on this matter, initiated by the RDMA, suggests that the Dutch Supreme Court put too much emphasis on underlying causes and not on the suffering when evaluating the doctor's actions. See J H Dijkhuis, *Op zoek naar normen voor het handelen van artsen bij vragen om hulp bij levensbeëindiging in geval van lijden aan het leven* (Utrecht: KNMG, 2004).

⁴⁹ This article cannot do justice to the complicatedness of the disease and limiting a description to the deterioration of faculties only seeks to convey the central message which has ignited the debate. The description is based on the one used by the US Alzheimer's Association. See http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp (accessed 7 August 2009).

⁵⁰ See, for example, the Belgian writer Hugo Claus, "Hugo Claus Kiest Eigen Afscheid" *Trouw*, 20 maart 2008 (<http://www.trouw.nl/nieuws/europa/article1798908.ece> (accessed 7 August 2009)).

Alzheimer's.⁵¹ Although a welcome development as we always applaud technological advancement, it does complicate end-of-life decisions even more. What do a doctor and a patient do when confronted with this new information? Does it suggest an effective treatment option for Alzheimer patients, fighting at least the symptoms and stopping cognitive deterioration, indeed, restoring cognitive faculties? Does the information impact upon the evaluation of suffering? How can the effects of a life-long dependency upon this medicine, without knowing whether it will continue to work, be determined? Does this uncertainty impact upon how suffering is experienced? Would patients appeal to existential suffering rather than to suffering which can be more objectively (medically) determined as hopeless and unbearable? Finally, and more provocatively: is it an option to use medicine as a means to recall patients from their Alzheimer's slumber and state of deterioration in order to confirm that they persist in their decision to have their lives ended, made as indicated in a living will? Of course, the results are results from clinical trials only but how seriously will these results be taken by those suffering from Alzheimer's and by their doctors?

This example shows that increased information does not make making decisions any easier. Instead, it shows that technological developments are not the linear improvements as we might like to believe but rather carry with them side effects which are either ignored or remain invisible. These side effects also manifest themselves in new (ethical) questions and dilemmas. All decisions are made in a state of continuing uncertainty. The conclusion is that by looking at information in this way all decisions are ultimately made provisionally. It shows that self-determination demands courage – the courage to make this leap of uncertainty. This can only be done when one realises that self-determination is ultimately an ethical matter and only secondarily a matter of (technological and medical) information.

⁵¹ E L Tobinick and H Gross, "Rapid cognitive improvement in Alzheimer's disease following perispinal etanercept administration" (2008) 5 *Journal of Neuroinflammation* available at <http://www.jneuroinflammation.com/content/5/1/2> (accessed 3 April 2009).