# THE MAINTENANCE OF LIFE

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# THE MAINTENANCE OF LIFE

*Preventing Social Death through*
*Euthanasia Talk and End-of-Life Care —*
*Lessons from The Netherlands*

Second Edition

## Frances Norwood

*This book is dedicated in loving memory to*
*Frances H. Norwood and Joseph Norwood, Jr.,*
*and all the other mothers and fathers, sisters and brothers,*
*wives, husbands, and grandparents who gave us*
*something really special before they died.*

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# Series Editors' Preface

## Life and Death:
### Beginnings, Endings, and Meanings

*Andrew Strathern and Pamela J. Stewart\**

We are very pleased to see this new and updated edition of Frances Norwood's notable work on issues of life and death surrounding the topic of euthanasia. The deep relevance of her study has been underlined by developments in a number of countries where legislation has been enacted on euthanasia since the first edition was published, mostly legislation moving toward its controlled legalization, in step with changes in public opinion. Norwood's theoretical and analytical frameworks on culture, discourse, and forms of medical practices which she brought to bear in this book remain important in the current edition, as well as her ethnographic approach that yielded the unexpected finding that euthanasia talk could lead to a prolongation rather than a curtailment of life. Such talk depends on the ongoing ability of persons to engage in considered discussion, and this becomes problematic in cases where someone is suffering from dementia, or else is a long-term sufferer from major depression and its resulting pain. Connected here, therefore, is the question of what kinds of conditions should be eligible for discussion about the right to die. Circumstances that make these issues pressing include the tensions inherent in modern life, increased average life span, changes in family dynamics, and resulting patterns of loneliness among older people living on their own. The Netherlands case provides, as Norwood shows, unique pointers toward thinking about end of life issues of these sorts.

Norwood's deeply thoughtful exploration of euthanasia and related practices in The Netherlands induces us to contemplate how death, seen in secular terms as the final event in a life, is, or can be, or should be, dealt with in circumstances when curing sickness or indefinitely prolonging

that life are not perceived options. The end of life, like the beginning of it, is always potentially difficult, even traumatic, for the network of kin and friends as well as for the dying person. Its meaning must be very different in contexts where cosmological visions imply an afterlife from those in which such visions are attenuated or absent. And attitudes to euthanasia, as well as to suicide, must vary with cosmology also (for an example from the Pacific see Stewart and Strathern 2003). If life is a gift from an omnipotent God, it may be argued that only that God can determine when it should end, and it can thus be expressed in phrases of acceptance such as "It was his/her time", or "an act of God". So, too, with life's beginnings, in conception and parturition.

Abortion (averting the beginning of life) and euthanasia (causing the ending of it) stand logically in similar spaces of indeterminacy or disapproval, depending on the prevailing cosmology. The Christian doctrinal background in many places, including The Netherlands, would lead to such a presupposition. And in addition to religion the state and its authority over people are likely to be involved. For reasons that must have to do with deeply held predispositions, abortion (under specific circumstances) may be permitted in practice by the state whereas euthanasia may not be. At the end of life an adult person has long been enmeshed in the politico-legal structures of the state, their identities and potentialities categorized, filed, and put into place. Their death, then, may be thought of as belonging more to the state than the termination of life prior to a birth. But, with progressive secularization and rationalization of practices, the state may come to embrace, and at the same time circumscribe practices previously tabooed by custom or religion. Norwood suggests that this role of the state may correspond to a secular faith in society, replacing a faith in God.

The term euthanasia itself implies something that is "good", from its Greek roots, "well-dying" (parallel with "well-being," we might say). The term also carries an echo of the concept of "the good death", defined differently in different culture-historical ways, but sometimes implying a peaceful end, without undue suffering, of a person surrounded by sympathetic kin and friends, who will also give the person, once passed away, a "good funeral".

Issues of terminal care may be involved. When should care become palliative rather than an aggressive attempt to cure a condition? The volun-

tary choice of a person to move from hospital to home or hospice is a mark of a decision to let life go. Euthanasia, in concept, takes this move one step further, by making death a matter of personal agency rather than a passive acceptance of events that must be considered beyond one's control and allowed to take their course. A decision of a person who feels that their life is effectively at an end simply to die without any artificial assistance at all is sometimes portrayed in works of art, and is not classified as euthanasia, although it is that person's active effort to achieve a good death as they see it. A person may be kept in a nursing home for a long time and remain passively in existence until some minor condition may end their life. They may have willed this or even looked forward to the end, signaling this by an unwillingness to interact much even with kin, or by choosing which kin to interact with and which not as a mark of their continuing agency. When they finally pass away, perhaps in sleep, the event is likely to be described as 'a blessing in disguise'. In a society that valorizes individual choice but also recognizes that death in a hospital is not ideal, passing away in sleep at home takes the place of the 'good death' of a person surrounded by kin. In one case we know, the person was receiving regular visits from hospital care staff following an operation, and they found him on their morning visit passed away and lying on the floor of a room in his dwelling. His friends commented that he probably died peacefully while asleep. They also commented later that he had a 'good funeral', because many people came to it. Such a good attendance is seen as a marker of the deceased person's social standing, and it affirms their ongoing relations in the local network. On the other hand, there is also an uneasy sense here that a person should not be lonely either while alive or at the time of their death. Loneliness, in turn, as a product of isolation, can be seen as a risk factor, separating persons from their potential sociality, and making them more prone to depression. Home visits by doctors, such as are a part of The Netherlands system, can help to counteract this risk.

Two characteristics of The Netherlands system of medical care are very pertinent to Norwood's whole study and its findings. One is the practice of making house visits that we have just noted. This stands out in stark contrast to contemporary USA practices. The other, most relevant to euthanasia talk, is the emphasis on '*overleg*', consultation leading to consensual decision-making, arrived at carefully and slowly and with safeguards against premature decision-making built in.

In terminal cases the actions of care-givers and visitors are bound up with the idea of compassion. Medicines are administered to alleviate pain or induce sleep. The person's agency and experience become constrained. It is in circumstances like this or when such circumstances are already envisioned or anticipated that discussions about the eventuality of death are likely to reach into people's consciousness. Until then, a patient may be expected to, or may expect to, fight for life, a fight which begins as a fight to get well, to be cured, and this process may continue as a self-sustaining fight for each succeeding day of living existence itself. When a patient chooses to be admitted into a hospice there is already an anticipation of death and an entry into a pre-death state of liminality.

Norwood looked into these issues and processes in both The Netherlands and the U.S.A. Her carefully constructed investigation is also in part framed by her own reflexive subjectivity in relation to the deaths of her own mother and father, with an increment of empathy resulting from her own experience. The duality of the anthropologist as observer ("subject") and the people she studies as observed ("object") is here definitively transcended. An even more striking example of this process can be found when an anthropologist discusses and analyzes their own experience with a particular condition, such as Emily Martin (2007) has done in her book on bipolar disorder, in the course of discussing the same topic in a broader fashion. Norwood explicitly lets us see in her own life some of the concerns that others see, and she has studied, in theirs: that is, the experience of the deaths of kin or associates. It is the more compelling because of the inevitability and universality of the experiential issues involved.

From her detailed empirical studies in The Netherlands, Norwood brings forward to our attention two surprising results and one informative factor for making comparisons. The first surprising result is one we have already noted: that "euthanasia" is often talked about as a possibility which can occupy the attention of a patient and their social network for a period of time without issuing in an actual decision to carry it out or the final implementation of an act of voluntarily ending the life in question. During this time the life of the person can also be reviewed and reflected on, over and above the possible struggle and pain of daily survival, precisely because of the potentiality of setting a date for the death itself. The process can also be shared rather than one that is only introspective. This gives us the second surprising result, that talk about euthanasia may be

seen as having a palliative function, even prolonging life while discussion about it goes on, and keeping the patient alive enough to think about what their life has meant and continues to mean and the circumstances in which they would or would not be content to die. Euthanasia talk is therefore as much about life as it is about death. That is, it is about life as a social phenomenon rather than just a matter of biology. Norwood begins her study with an early field experience in which a man points to a picture of his wife on the wall, and he says that his wife is there in the picture, not the physical being lying terminally ill on the bed nearby. We had a parallel, even more poignant, experience in Scotland on one occasion when we were interviewing a man about his work on the local land estate. It became evident that his wife was suffering from memory loss, and as he ushered us out he said that he wanted us to go through the front area of the house, where he showed us a cabinet filled with prize presentation cups his wife had won as a schoolteacher before she had retired. "This is what she really was", he said. This was how he wanted to remember her and have her memory honored by us.

A further point—and this is the informative factor referred to above—is that the general medical practitioners (*huisarten* in Dutch) in The Netherlands play a close, sympathetic, and mediating role between the state, the patient, and family and kin in the process of euthanasia talk. The role is authorized by the state, and the doctor will eventually play an active part if the patient decides to go through with the procedure of voluntary death. This places a large responsibility on the doctor, which is fulfilled exactly by the house visits, the lengthy discussions, and the whole process of careful deliberative discussion (*overleg*) which Norwood remarks is characteristic of Dutch social culture generally. Given the stereotypical patterns of segmental, single-stranded, impersonal, and routinized interaction with primary care physicians in many contexts in the U.S.A., the model of the caring practitioner who makes home visits and gets to know people well seems to be a very valuable one to keep in mind as also potentially beneficial outside of the contexts Norwood is discussing concerning euthanasia.

The reference to euthanasia talk as a kind of palliative care, in which doctor, patient, and social network co-operate reminds one of the functions of hospice care in many places where euthanasia as such would not be legally permitted. From The Irish Times Weekend Review section for Saturday, December 13, 2008 (published in The Republic of Ireland) we

culled a lead article with the title "Living and dying with dignity". The article foregrounds the breadth of functions of hospices run by the Irish Hospice Foundation, with the aim of offering "more people comfort, friendship and a second home when they need it most" (loc. cit., p. 1). One patient is prominently quoted as saying: "I had been under the illusion that the hospice was a place to die, but it's not. They make it so pleasant and make you feel like somebody cares" (ibid.). The same article reports a first national survey in Ireland conducted in 2004, in which 67% of people wished to die in their homes, without pain, conscious of those around them and with their "loved ones", i.e., kin or friends (ibid.). Yet, it goes on, in practice two thirds of the approximately 30,000 people who die each year in Ireland are in hospitals at the time of death (ibid.).

Here we interpret further the implications of the newspaper article discussed above. Efforts to increase the numbers of hospices and to expand their range of services are clearly designed, we suggest, to close the evident gap between people's ideal wishes and the limitations of what hospitals can do. Hospices are in between hospital and home. They can provide some professional medication, and they can also be more like a home. In a very broad sense, then, they provide both assisted living and assistance with dying. If to die at home is an ideal, for some people, we may note, euthanasia allows this to happen in a planned way. The patient is not whisked away in an ambulance for heroic surgery or medication, but may quietly prepare or be prepared to die.

The same section of *The Irish Times* featured on its back page (p. 16) a brief report, called "the television story of the week", in a documentary film of the "assisted suicide" (loc. cit., p. 16) of a person who was suffering from motor neuron disease. The theme of "dignity" is replayed here in a different context, since the clinic in Switzerland where the event took place is the "Dignitas Clinic" (ibid.). The film was reported to have shown the patient drinking a lethal dose of barbiturates through a straw, falling asleep, and dying within half an hour. The newspaper reporter writes: "He died in peace, in the presence of his wife" and "with a Swiss doctor and with the film crew" whom the dying person "had invited to witness his parting" (p. 16). The piece ends with "I hope he has found the peace he sought", a secular echo of the liturgical requiescat in pace, without its original cosmological implications of the dead waiting in peace for the second coming. The search for peace is clearly a theme shared by these two articles

at front and back of *The Irish Times Weekend Review*. Dividing them is the question of the avowed and legitimate means of how such peace may be obtained.

Interest in a case like this reported in *The Irish Times* is transnational. We (AJS and PJS) were in Taiwan on research in December of 2008, and we read another account of this case, reported directly from London, which appeared in The China Post, a local newspaper there in Taiwan. This report noted that a British television network came under criticism in the U.K. for screening the film. It notes that "this was the first time British television has shown someone committing assisted suicide" (The China Post, Thursday December 11th 2008, p. 2). The man whose death was depicted, who was 59 and partly paralyzed from his condition, had been a University Professor, the report says, and had wanted the film made so that people could see how such a death could be comfortable. He gave as his reason for wishing to die that otherwise he would continue to suffer and to inflict suffering on his family (ibid.). Anti-euthanasia activists, however, declared that it was irresponsible to show the film because to do so would be "euthanasia voyeurism" and "would create a false impression of a growing demand for assisted suicide in Britain" (ibid.). It would also strengthen pressures felt by people about imposing on "loved ones [kin], carers or a society that is short of resources", a campaign group called "Care Not Killing" declared (ibid.). Such reports indicate clearly how controversial the subject is; they also show that it is of great and international public interest. To some extent the issue becomes more difficult with the secularization of society, which opens the way to such debate. To some extent, also, it is due to the ability of medicine to keep people alive or artificially alive. One way and another, the question of whether a person can legitimately be the instrument of ending their own life remains a matter of considerable concern in those countries with relatively long life-expectancy figures and relatively advanced medical capacities. Dignity does seem to be a central matter in the debates. The Netherlands rule regarding euthanasia is constructed with this matter in focus. The person who, exercising their free will, has decided to end their own life, is in a structural position analogous to that explored by Giorgio Agamben in his book Homo Sacer (1998), a person who cannot legitimately be sacrificed but whose killing also cannot necessarily be punished (Agamben 1998: 81); provided it is carried out in a prescribed way, we might add. Suicide or assisted suicide may be regarded

as within the zone of taboo; or simply in the zone of the liminal, on the margins of legitimacy. All of these characterizations reflect the complex feelings that surround the topic and relate it to the overall mystery and liminality of the cycle of life and death, intimately related as well as in a sense opposed, often studied by anthropologists in conjunction with ideas about spirits, ghosts, and the "otherworld" that frames the life-span of the person in society. Attitudes toward death are bound to vary enormously according to ideas of this other world of spirits. "Gone to a better place" becomes available as a euphemism in a cosmographic world with an image of a "Heaven" in it. In the same religious world, the saying "The wages of Sin is death" hints of the opposite of Heaven, Hell. Where such notions are less strong, or absent, focus is likely to be on the circumstances of death itself, whether it is peaceful or troubled and the like. Still, the idea of a journey can be present, wherever the destination is thought to be. Thus, a funeral well attended by kin and friends may be described as having made "a good send-off" for the dead person.

Since birth and death, as well as other cyclical events, are tied in with kin relations, the roles of kinsfolk are likely to be crucial. The place of such kin in debates about how terminal illness is to be handled and whether a person can die "at home" is always likely to be significant. In nuclear family situations this burden is quite likely to fall on spouses; or on adult children. The extent of the obligations of such care-givers is by the nature of the relationships involved likely to be difficult to measure, since such obligations are open-ended, universal, and at the same time subject to agreements between those involved. At any rate, as with so much of contemporary life which is not conceptualized as belonging to the realm of kinship as such, in practice kin ties and kin networks tend to be involved in decisions about life and death, and it is within the domains of kinship that the cyclicity of life and death is played out.

Dr. Norwood's study explores these and many other matters with great detail and ethnographic insight. Her book contributes deeply both to applied topics in medical anthropology and to a philosophical anthropology of life and death. Indeed, she shows that these two topical arenas are closely connected, since basic philosophical ideas and cognitive schemata, expressed in relational or secular terms, create the contexts in which arguments about euthanasia are fought out. Dr. Norwood recommends that The Netherlands approach to these arguments can fruitfully be considered

in other contexts, such as those in the U.S.A. Her work makes a most interesting contribution to discussions in Medical Anthropology and we are very pleased to include it within the Medical Anthropology Series of books with Carolina Academic Press.

Angkemam House, Catrine, Scotland &
Cromie Burn Research Unit, University of Pittsburgh
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PJS and AJS

# Note

(*) Pamela J. Stewart (Strathern) and Andrew J. Strathern are a wife-and-husband research team who are based in the Department of Anthropology, University of Pittsburgh and co-direct the Cromie Burn Research Unit. They are frequently invited international lecturers and have worked with numbers of museums to assist them with their collections. Stewart and Strathern have published over 50 books and over 200 articles, book chapters, and essays on their research in the Pacific (mainly Papua New Guinea and the South-West Pacific region, e.g., Samoa and Fiji); Asia (mainly Taiwan, and also including Mainland China and Inner Mongolia, and Japan); and Europe (primarily Scotland, Ireland, Germany and the European Union countries in general); and also New Zealand and Australia. Their most recent co-authored books include *Witchcraft, Sorcery, Rumors, and Gossip* (Cambridge University Press, 2004); *Kinship in Action: Self and Group* (Prentice Hall, 2011); *Peace-Making and the Imagination: Papua New Guinea Perspectives* (University of Queensland Press with Penguin Australia, 2011); *Ritual: Key Concepts in Religion* (Bloomsbury Academic Publications, 2014); *Working in the Field: Anthropological Experiences Across the World* (Palgrave Macmillan, 2014); *Breaking the Frames: Anthropological Conundrums* (Palgrave Macmillan, 2017) and *Diaspora, Disasters, and the Cosmos: Rituals and Images* (Carolina Academic Press, 2018). Their recent co-edited books include *Research Companion to Anthropology* (Ashgate Publishing, 2015); *Exchange and Sacrifice* (Carolina Academic Press, 2008) and *Religious and Ritual Change: Cosmologies and Histories* (Carolina Academic Press, 2009) and the Updated and Revised

Chinese version: Taipei, Taiwan: Linking Publishing, 2010. Stewart and Strathern's current research includes the topics of Eco-Cosmological Landscapes; Ritual Studies; Political Peace-making; Comparative Anthropological Studies of Disasters and Climatic Change; Language, Culture and Cognitive Science; and Scottish and Irish Studies. For many years they served as Associate Editor and General Editor (respectively) for the *Association for Social Anthropology in Oceania* book series and they are Co-Series Editors for the *Anthropology and Cultural History in Asia and the Indo-Pacific* book series. They also currently Co-Edit four book series: *Ritual Studies*; *Medical Anthropology*; *European Anthropology;* and *Disaster Anthropology* and they are the long-standing Co-Editors of the *Journal of Ritual Studies* [Facebook: https://www.facebook.com/ritualstudies]. Their webpages, listing publications and other scholarly activities, are: http://www.pitt.edu/~strather/ and http://www.StewartStrathern.pitt.edu/.

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# Preface

This second edition comes ten years after the first book. A lot has changed in the greater context of healthcare since the first edition — with the passage of the U.S. *Affordable Care Act* in 2010 and the current assault on healthcare heralded by the election of Donald Trump in 2016. Up until the 2016 elections, assisted dying policy was on the upswing around the world with laws passing in several countries and in a number of states in the U.S. The U.S. — and the world — is in a period of social unrest and where end-of-life policy will fall is just one of many issues that hang in the balance.

This edition updates key events that have occurred since the publication of the first book in 2009 and outlines where I think end-of-life policy might be going given these events. What has not changed, however, is the ethnography on which the original book was based. Ten years later, this book continues to be about how people live and die and additional research I conducted in The Netherlands in 2008 and 2012 and correspondence with countless Dutch providers and researchers since the publication of my research suggests that the process of euthanasia in The Netherlands has not fundamentally changed.

When I mention to people I meet that I study death and dying, I invariably get one of two responses. Sometimes the person opens up with a heartfelt story of the death of a loved one or the person shys away from the topic with a comment like, "Isn't that depressing?" and nonverbal cues that tell me that they really don't want to know the answer to the question. The answer is yes, death is depressing, but there is also something beautiful and life-affirming about witnessing the passing of a human life. Studying with people who were dying and with people who cared for them taught me something about death, and about life. Death is hard and by witnessing it so intimately, I came to a new understanding of how valuable life is and I learned a little bit more about myself and what I want from life.

This book is about the day-to-day experience of death in a culture that has experimented with some new ways of supporting modern death. This book is for anyone interested in learning more about death in another culture in order to gain some insight into life and death where you live. This book is written for persons who are dying and for the family members who care for them. It is for healthcare professionals, bioethicists, policymakers, anthropologists and other social scientists interested in learning how to make a better way at the end of life.

This book is also intended for those on both sides of the euthanasia and assisted suicide debates. Most chapters begin with an extended excerpt of someone's experience, highlighted by italics in the text. Based on in-depth interviews and observations with patients, family members, and healthcare practitioners, these excerpts provide readers, who both support and oppose assisted dying policies, information about how assisted dying occurs on a day-to-day basis. They include direct quotes from taped interviews with participants (marked in the text by quotations) and paraphrased quotes and observations gained from fieldnotes taken during or immediately following an event and often double-checked by interviews with participants following an event. While individual names have been changed, the stories—the events, the people, and the locations—are real.

# Acknowledgments

(Norwood, Frances 2006 A Hero and a Criminal: Dutch Huisartsen and the Making of Good Death Through Euthanasia Talk in The Netherlands. *Medische Antropologie* 18(2):329–347).