

Thinking the Obvious:

Determination & Indetermination in a Voluntary Death

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Abstract

This article describes and analyzes the negotiations for and arrangements of an assisted voluntary death in Switzerland for a particular person, Peter. His approach to an assisted voluntary death is observed in two moments, making visible two interconnected concerns: The first is to take up one moment in the process of evaluation, the clinical examination, and its relation to the “obviousness” of a language of choice, concerning the request for assistance with suicide. The multiple significations within the situation of evaluation and discussion are grasped with the help of Roland Barthes’ term *le Neutre*, or “the desire for the Neutral”: a search for a mode of semiotic engagement that eludes, or ruffles, signifying oppositions. The second major stake of the article is to make visible an ethical and aesthetic question pertaining to the gestures of assisted suicide: a question of how to grasp the semiotic determinations and indeterminations in this manner of dying. The article takes up the motion in gestures, and their significations, in order to grasp their ethical stakes, relative to a double iconographic tradition, that of compassion and lamentation, through attention to the actual form given to Peter’s death.

Cet article décrit et analyse les négociations et la mise en œuvre d'une mort volontaire assistée en Suisse pour une personne, Peter. Sa démarche vers une mort volontaire assistée est observée en deux temps, rendant visible deux préoccupations interconnectées: la première est d'aborder un moment dans le processus de l'évaluation, l'examen clinique, et son rapport avec le caractère évident d'un langage de choix concernant la demande pour l'aide au suicide. Les significations multiples dans la situation d'évaluation et de discussion sont saisies à l'aide d'un terme de Roland Barthes, « le Neutre », ou « le désir du Neutre »: la recherche d'un mode d'engagement sémiotique qui déjoue des oppositions signifiants. Le deuxième enjeu majeur de l'article est de rendre visible une question éthique et esthétique concernant les gestes du suicide assisté: c'est une question de savoir comment saisir les déterminations et les indéterminations sémiotiques dans cette manière de mourir. L'article reprend le mouvement des gestes, et leurs significations, afin de saisir leurs enjeux éthiques, relatifs à une double tradition iconographique, celle de la compassion et de la lamentation, par l'attention de la mise en forme réelle de la mort de Peter.

Keywords: Voluntary death; Switzerland; Neutral; Indetermination; Gesture in dying

It must have been early 2013, I no longer remember exactly when, that I found the film *Terry Pratchett: Choosing to Die*, on YouTube (Russell 2011). My newborn son had just fallen asleep on my chest. It could have been February; I recall drowning out the sound of the rain with my headphones. What had begun as a nascent thought, a possible new project about assisted suicide in Switzerland, was nourished by the prospect of moving from San Francisco to Paris, later in the year, to begin doing the inquiry.¹ Sitting there at our dinner table, small lungs pressing in and out against mine, I watched the late British comic novelist Terry Pratchett, then suffering with Alzheimer's, narrate how he embarked on making a film about assisted suicide in Switzerland, endeavoring to meet people making the trip to Switzerland to die, so as to pose to himself the question, fundamentally an ethical question, of whether he too would do the same. The film was a beginning and an orientation in order to begin honing what I thought might be a question at stake in the practice of assisted suicide: a question of form and signification. It wasn't yet the three years I have spent so far attempting to contact people who are in the midst of, or are beginning, their request for assistance with suicide from associations in Switzerland. There wasn't yet reflection based on the panoply of people I would come to meet – people wishing to end their lives, their husbands, wives, sons, daughters, Presidents and Vice-Presidents of associations for assisted dying, volunteer accompaniers, home palliative care teams and their patients whom we visit, psychiatrists at teaching hospitals, pharmacists in different cities, police officers and undertakers (and so on and so on). And yet, this film, and in particular the story of one person within it, Peter, presented me with both a story of a singular life, and an image of dying, an image I would come to revisit again and again, whose forms, stakes and significations would accompany me, and would be echoed, as I too would come to follow others from their requests for assistance with dying to the form and manner of their death.

What struck me in observing the arrangement and *mise-en-scène* of Peter's death, in the film, was that it seemed to me, and still seems to me to be the case, that there was a language lacking for adequately grasping the ethical, aesthetic, affective and intellectual qualities of this relatively new manner of dying.

¹ An "incoming" fellowship from the Maison des Sciences de l'Homme allowed me to begin the inquiry, based at the Institut Marcel Mauss in Paris. The work was subsequently funded by the Wenner Gren Foundation and an IFRIS post-doctoral fellowship, based at CERMES3. I am grateful for the institutional support and material means.

Or else, and otherwise put, that within the form of the film, and within the genre of that kind of documentary, echoed in some arenas of professional discourse, it wasn't possible to explore such a language and such qualities. What had prompted the nascent idea for such an inquiry was the thought that assisted suicide, statistically speaking a minor phenomenon in terms of how people today die (Steck et al 2014), might be considered as a significant historical intervention into how human beings die: a reconfiguration of available practices so as to give a new form and manner to dying as an experience. Suicide and euthanasia are social facts, and each has its own history, of course: watching the film, I was bolstered in thinking that what seemed specific about the reconfiguration produced by practices of assisted suicide was the invention of a negotiated form for voluntary death, which is mediated in relation to conventions of medical knowledge and judgment, but which endeavors to give a different form, a better form, a less nefarious form, to the relations of power between doctors and those who wish to end their experience of suffering (c.f. Stavrianakis 2016).

The language of "choice" has been primed in relation to this activity, principally within the medical ethics and bio-ethics literature (both as a positive value and as an ideological illusion, c.f. Dore 2011; Humphrey 2001; Quill 2004) as well as amongst participants in the practice. Such a language is both understandable and yet insufficient. At the time, when watching the film for the first time, I did not have an alternative. In what follows the first major stake of the article is to take up the activity of this form of death, the process of negotiation that it involves, its relation to the "obviousness" of a language of choice, and the multiple significations which can be grasped within it, with the help of Roland Barthes' term *le Neutre*, or the desire for the Neutral: a search for a mode of semiotic engagement that eludes, or ruffles signifying oppositions, such as a binary pair of choice and obligation.

The second major stake of the article is to make visible an ethical and aesthetic question pertaining to the gestures of assisted suicide shown in the film: a question of how to grasp not only the pragmatic determination and indetermination in the specificity of this form of dying but also semiotic determination and indetermination. The gestures observable in the film of Peter's death, I will suggest, connect the observer to a double iconographic tradition that will aid us in grasping a second aspect of the

significance of assisted suicide as a reconfiguration of the experience of dying: the iconography of compassion and lamentation, whose articulation, form and significations can be grasped through a mood of the Neutral. I will read the movement and motion of gestures in dying made visible in the film in order to try and grasp their ethical stakes, relative to these gestural traditions, through attention to the actual form given to one person's death, Peter's.

To whom it may concern

Inside the neat yellow folder, marked *medical*, amongst email exchanges with friends, doctors' reports, letters to lawyers, and the letters exchanged with *DIGNITAS – To live with dignity – To die with dignity* (hereafter DIGNITAS), the organization that helped Peter to end his life, I came across a letter:

9th November, 2010

To whom it may concern,

In March 2009, I was diagnosed with Motor Neuron Disease [...] There is no treatment for this disease and no cure [...] This is a terminal disease, culminating in restricted breathing, loss of mobility and loss of speech, amongst other undignified and debilitating conditions. As I have no wish or intention to suffer such humiliating and truly unpleasant symptoms I have, not surprisingly, investigated methods of escape from this intolerable situation by way of dignified dying. For reasons I believe are obvious, the dignified dying option is the preferable choice and the least distressing course of action for everyone concerned, and principally, myself. [...]

Peter, a retired hotelier, had contacted DIGNITAS fifteen months previously. He left for Zurich one month later, with his wife Christine, and without their daughter, in order to die at the premises of DIGNITAS, an association that, besides other services, assists with voluntary death.² Peter lamented having to travel to

² Founded in 1998, DIGNITAS – To live with dignity – To die with dignity is a nonprofit member's society which provides counselling about advance directives, suicide attempt prevention, palliative care and end of life issues, advocacy in patient-doctor relations within medical settings and provides a service of assistance with voluntary death, for members, both residents and non-residents of Switzerland, at an apartment which the association maintains in the canton of Zurich. In 2015 the association had 7'291 members and assisted 222 people with their voluntary assisted death (statistics taken from DIGNITAS website). In the same year Exit Deutsche Schweiz, which has approximately 95,000 members, assisted 782 people to end their lives. Exit Association

Switzerland. He was highly critical of British society's failure to address the punitive character of the law on assistance with suicide, which remains an illegal act in the U.K. despite eighty years of active campaigns. In order to bring "light and air" to the subject, Peter agreed to make a documentary about his assisted suicide, produced by the BBC and broadcast the year after his death (Russell 2011).

It was through the documentary that I first learned of Peter's life and the manner of his death. In October 2015 I contacted Christine, in order to ask if we could talk about her husband's decision. She agreed, specifying that she had refused all efforts by journalists who contacted her after the screening of the documentary. The fact that Peter wanted to bring what he considered to be "an absurd situation" before "as many members of our society as possible", is perhaps one reason, among others, that Christine, agreed to both talk with me and to allow me to consult Peter's files and personal reflections. When we met, over two days at her home in December 2015, on the island of Guernsey, I explained that I was interested in the specificity of Peter's decision to die within a wider program of inquiry around assistance with suicide. It seemed to me that we had a reciprocal understanding of what I was up to: to try to understand how people suffering with different illnesses, and the organizations whose help they solicit, come to an agreement that it is appropriate and possible that a person ends their life voluntarily. Moreover, I explained that the endeavor was to grasp the possible significations of such a manner of dying, given the current political and legal obstructions to such a form of dying in the majority of countries.

I use the documentary as a principal means to grasp both Peter's engagement with the medical process for making a judgment as to whether he could end his life, as well as to observe the manner in which his life ended. Rather than reconstruct the entirety of the negotiations between Peter and DIGNITAS, I focus on two situations of interaction made visible in the documentary, which offer channels to pose questions about the determinations, indeterminations and open significations of such a mode of dying: the situation of clinical examination and the situation of dying. As Silvan Luley of DIGNITAS kindly

pour le droit de mourir dans la dignité (Suisse Romande) in 2014 had 20,507 members and assisted 175 people to die. Both Exit associations only accept Swiss citizens as members.

explained to me, and as I will explain shortly, my orientation excludes a focus on what DIGNITAS considers to be “the first and most important situation: the examination of the request by DIGNITAS. All requests by members of DIGNITAS are examined by the association before these are handed to one or several Swiss medical doctor(s), each of whom is independent of them, that is to say, they are not employees of the organization.”³ The key moment I have selected are prefigured and given sense through the life history and descriptions of Peter that Christine generously shared with me, and through the medical documents and negotiations with the association, which Peter meticulously archived.

A word is necessary, before following Peter’s story, about the development of the documentary and the selection of Peter as a key participant. The film was directed by Charlie Russell, a young British documentarist whose first film was about his grandmother, the author Dame Beryl Bainbridge, as she tries to live through the “the curse” of her final year—she was convinced that as with everyone else in her family, she too would die at age 71. Russell subsequently made a film about another author living with a prefiguration of death, comic novelist Sir Terry Pratchett, as he came to terms with a diagnosis of Alzheimer’s disease. In the wake of that film, Pratchett began to explore assisted suicide in Switzerland as a possible way of dying. Pratchett and Russell collaborated in order to try to find a few British citizens whose cases had been accepted by DIGNITAS. DIGNITAS wrote to all its British members, to ask if they would allow someone who was also ill and considering assisted suicide, to follow them. Peter, I learned, had known Pratchett well in his younger days in Somerset, when he and Christine owned and ran the 5 star luxury hotel *Ston Easton Park*.⁴ The pair, I was told, used to joke together, with good doses of morbid humor, about how they would end their lives if they found themselves stuck with interminable suffering.

³ In our email correspondence Mr. Luley underscored that “this is an important quality element for us: An examination by two independent parties. In fact, with DIGNITAS’ quality standards, there is even a 3-party-examination: (i) DIGNITAS; (ii) the independent medical doctor and then (iii) the “accompanier/befrienders” who “do” the actual conducting and preparation of the event of the assisted suicide. The accompaniers are independent to the extent that they can refuse to carry out the accompaniment. In fact, they are obliged to refuse in circumstances where they realize that the prerequisites for a legal assisted suicide are no longer present. For example: if the person loses the capacity of discernment in the hours after the doctor’s consultation and the granting of definite consent for the assisted suicide, including the prescription of the Pentobarbital.”

⁴ The reader will be aware by now that I have intentionally left out certain details about Peter, such as his age and his background, albeit offering one pertinent contextualization of his socio-economic position (high). The statistical fact that, among Swiss citizens who died through assisted suicide in 2003-2008, the majority of persons who did so were of a high socio-economic position is, of course, important and interesting, but beyond the scope of the paper insofar as it does not touch on the core stakes

Three observations

In re-describing Peter's experiences, his narratives, his gestures even, ones already, if partially, mediated and expressed in the form of a documentary, through his personal records and exchanges, and through the re-telling of his life and his death by Christine, my aim is to ask how an observer could grasp a voluntary death, an event for which the signification seems to be "obvious", as Peter himself indicates. My aim is to observe, albeit through post-facto reconstruction, his decision and his manner of dying. Three of Peter's observations are important to underscore, which will assist me in clarifying some questions at stake in this inquiry about the contemporary significance and signification of assisted suicide: (1) that he suffered from an illness for which there is no cure and that would cause him to die in a manner he characterized as "unpleasant and humiliating". (2) That for Peter, finding a "method of escape" is better for everyone and principally himself. (3) That recourse to "dignified dying" is "obvious" given this situation.

Each of these observations drawn from Peter's letter provides us with a theme for inquiry. First of all, it is important to insist on the fact that it is not mandatory for the associations that facilitate assistance with suicide in Switzerland that an illness is incurable and lethal—what is often called "terminal illness", as was the case with Peter. A key question, beyond my scope in this article, is what particular illnesses, and what experiences of illness, justifies assistance and in the eyes of whom? It will have to suffice for me to state (rather than demonstrate) that there is no medico-moral norm that regulates acceptance of requests beyond two boundary conditions: that the person who requests assistance is capable of "discernment" and that the person can enact the suicide (drinking a lethal solution of barbiturate or opening the tap on a perfusion or activating a machine which pumps the medication into a perfusion) without aid. The act should be qualified by those present as a self-enacted ending of life, which is legally

of the article, namely, the determinations and indeterminations in ethical signification of such a form of death (c.f. Steck et al 2014). Despite the fact that Peter is referred to by his full name in the film, Peter Smedley, by referring to him only as "Peter" I wish to underscore the manner in which I take up Peter's situation as an individuation of a manner of living and dying (c.f. Macé 2016 201-282). By contrast I refer to Terry Pratchett as "Pratchett" since my concern is not to individuate his participation and practice. I do not want to treat Peter as a sociological instance, or a medical case, or as an example standing in for a general phenomenon. Peter's age, for example, is not, from his point of view or the point of view of any of the other persons concerned, a pertinent category in his decision or their decision to help him. What is important is that he had Motor Neuron Disease (MND) and did not want to die with the effects of advanced MND.

a suicide, of a reasonable person, and this qualification is either supported or contested by those who take care of the medico-legal consequences (the police, forensic medical examiners, and the public prosecutors who must open an inquiry after each suicide, only closing the case once it has been established that it was an assisted suicide conforming to the law).

Thus on the one hand, different situations, different illnesses, differences among individuals who work with assisted suicide associations, different Cantons, at varying historical moments, demand higher and lower degrees of justification and mobilization of evidence to fulfil these conditions of capability. There are also variable amounts of “evidence” that are asked for in order to demonstrate the precise state of the person’s illness and variable judgments about how severe the illness has to have gotten in order to justify assistance. In Peter’s situation, the collaborating doctor in Switzerland, who first read his dossier, wanted more recent neurological reports in order to have a clearer picture of the degree and rate of neurodegeneration before giving him a “provisional green light”. On the other hand there is the open question of whether those who are asked to accompany the one who requests assistance with suicide agree to the reasons given by the reasonable and capable person who wishes to die. Such requests and acceptance are squarely within the ethical domain of a demand for this-worldly compassion, of favor, or of grace. Such heterogeneity and open ethical terrain primes attention to two principal themes: how a judgment that a person can and should end their life is determined, and how it makes sense, if it does, i.e. the signification of the act.

Peter determined that assisted suicide is better for everyone and principally himself. How was this determination produced? On the one hand there is in operation a model of decision making centered on the individual, and often expressed within a language of “choice”. Fieldwork thus far has indicated that it is key part of the self-understandings of the people who participate in this practice. And yet this model is incomplete. The “decision” to die, on the one hand understood as a personal “choice”, a term which etymologically comes from a Proto-Indo-European root meaning “to taste or test”, and the decision to go towards one form of death and not another, is nevertheless also a judgment; that is to say, a discernment

and attribution of a quality or character to a situation which necessary involves others.⁵ The extra-individual character of a such determination can be investigated in two manners, without nullifying its individuated character: in biographical terms I will ask how Peter's decision has extra-individual determinants, leading to a judgment that could be shared. In terms of the situation of assistance with suicide, I will ask how during the period leading up to the act of ending life the situation requires arrangement and negotiation between participants. Moreover, in the observation of the act of ending life itself, the attribution of meaning to the act must take into account the signification given to it by the person concerned, and yet such meaning is also complemented by others, key among whom are the other participants in the situation, but also observers of the film, readers of the newspaper reports which followed the airing of the film and readers of this article.

A Swiss mechanism

Let me now clarify the arrangements of people and things that should come together, at this historical conjuncture in Switzerland, such that a person may end their life with assistance from others. The case of Switzerland is particular, and thus distinct from several states in the US, and distinct from the Benelux countries, insofar as assistance with suicide is conditioned by a legal means that is not a positive law: i.e. it does not stipulate positive criteria for the legality of helping someone to actively end their life. The associations that organize assistance with suicide since the 1980s have been legally facilitated through the stipulations of article 115 of the Swiss Penal Code, which considers assisting with suicide a crime if and only if the motive for assistance is "selfish."⁶ Such a stipulation, which stems from late-

⁵ I have decided to intentionally retain the use of three terms, "choice", "decision" and "judgment", in order to refer to three overlapping aspects of the pragmatics of negotiating and doing an assisted voluntary death: that the act must be able to be referred back to the will of an individual, understood as a choice, in keeping with one of the key legal conditions; that the act of going forward cuts of other possible activities and thus counts as a decision; and finally, in a pragmatic sense there is a third aspect of the act of going forward with the endeavor which involves the attribution of a mode of being to a situation that has been rendered determinate, which is how pragmatist philosopher John Dewey understands the practice of judgment (Tom Burke, *Dewey's New Logic: A Reply to Russell*, Chicago: University of Chicago Press 1994), 179.

⁶ I thank Silvan Luley for referring me to the English version of the Swiss Criminal Code with the translation of *selbstsüchtige Beweggründe, mobile égoïste, motivi egoistici*, as "selfish". Swiss Penal Code, Art. 115: <https://www.admin.ch/opc/en/classified-compilation/19370083/index.html#a115> One reviewer who clearly knows and understands the Swiss context well, suggested that I point out that the juridical context is one of "haziness", which is a *topos* sustained in many discursive domains about assisted suicide, in Switzerland. Nevertheless, it is important to underscore that whilst not a positive law, that is to say, whilst the law does not stipulate who can assist and be assisted, it is nevertheless not indeterminate regarding the constraint of the law: what constitutes a crime is to help someone to end their life for selfish reasons. The pragmatic ethical question of whether an

nineteenth-century expert legal discussions during the writing of the Federal Criminal code, eventually ratified in 1937 and which came into force in 1942⁷, renders Switzerland an exception to the majority of European countries, in which assistance with suicide, even for honorable reasons, remains a crime.

The legal frame in Switzerland, furthermore, provides no stipulation about the means or venue of such assisted suicide, with the vast majority of deaths occurring in private residences, either in homes of Swiss residents or in residences of associations which agree to help foreigners. A de facto practice emerged nevertheless in the mid-1990s: the provision of a lethal dose of a short-acting barbiturate by an “accompanier”, yet only after prescription by a Swiss medical doctor, from an assisted suicide association. Switzerland thus has the particularity of being the setting in which a practice has emerged for assistance with voluntary death that relies on medical authority for access to the means for suicide, but which is not necessarily encompassed by medical institutions. This practice is one in which a series of supports are arranged to shape whether and how a person can end their life.

It is possible to identify three supports put in place for all associations since the late 1990s: (1). *Expertise*: The preferred manner of dying is a lethal dose of barbiturate. Associations therefore require the collaboration and judgment of medical doctors. Doctors require medical reports indicating course of illness and treatments pursued, sometimes a “medical certificate” indicating the doctor’s appraisal of the situation, as well as the agreement of a doctor in Switzerland to write a prescription. (2) *Accompaniment*: Assisted suicide facilitated by these associations always involves the participation of at least one accompanier from the association (in the case of DIGNITAS there are always two present). The accompanier is usually a person distinct from the prescribing doctor, and with DIGNITAS this is a rule (see f.n. 2). For the associations that work uniquely with Swiss citizens, such as Exit ADMD, the accompanier who guides the assisted suicide may have an “ongoing” relation with the person who wishes to die, or else a more “punctual” relation, meaning that for some accompaniers, in certain cases, it is their practice to

individual should help another person to end their life is “hazy” only to the degree that it is an ethical question, an ethical question that cannot be arbitrated by right and in advance by the law, and which thus poses the entirety of the interest for an anthropological account of ethical practice.

⁷ https://en.wikipedia.org/wiki/Swiss_Criminal_Code

communicate regularly with the person who requests assistance, for example visiting them at home, encouraging the person to continue to live a little longer. For other companions they feel such involvement is inappropriate and restrict the practice of accompaniment to the event itself (Graber 2012). Thus the accompaniment, or “befriending”⁸ might be very short term, involving only one or two meetings, or else it might unfold over a long period, in which the sick person periodically calls for discussion of assistance with suicide, only to then relinquish their plan, and then subsequently followed by (yet) another request. Although difficult to generalize and formalize across all associations and all cases, let us simply say that between the association and the specific companion, relevant documents are prepared for the police, and a consent form is presented by the companion to the person, she explains it and makes sure it is signed. With respect to the procurement of the lethal dose of barbiturate, again, it is not possible to generalize across all associations. In the case of DIGNITAS, the office staff retrieves the prescription. The companion receives the prescription from the DIGNITAS office and with this retrieves the barbiturate (if someone from the office-staff has not already fetched it from a pharmacy). The companion also calls the police once the assisted suicide has taken place. Accompaniment expresses a person’s concern for the manner in which death is brought about for another. (3) *Narrative*: In the rapports between the person who prescribes, the person who accompanies, the persons at the office of the organization and the one who requests assistance with suicide, there is always elicitation of narrative about their wish to end their life.⁹ In particular the person who requests assistance must be suffering in one way or another in such a way that they can narrate the experience as warranting help with suicide. Narratives of the experience of illness, relative to a person’s request for help to end their life are then taken up within the multiple relations that make up the person’s life, such as those of kinship and friendship.

⁸ <http://www.befriend-at-the-end.org.uk>

⁹ DIGNITAS underscores that the relation between the person who requests and the office of the association is the longest stretch of time within which narrative is request, as the preparation of an assisted suicide will take around 3 - 4 months (for people from abroad) and sometimes longer

Assistance with suicide in Switzerland is a practice that the law neither positively frames (it doesn't say how to do it, who can help with it, or the reasons that must underlie the request) nor categorically forbids. Elicitation of narrative, the work of expertise, and of accompaniment, when brought into certain arrangements, can provide the turning point through which a date can be set for ending life.

Peter's choice

Driving from the airport to her home, Christine began to narrate Peter's choice to end his life within his family history: "A few years before Peter got ill, we sat down to do his family tree. And I said to Peter, oh look, no male member of the family lived past 72. His father died at 70." Peter's symptoms started at 69. Christine went on to explain the significance of Peter's father's death: he died in a hospital in Sussex, England. The cause of death was supposedly the infection in his leg subsequent to gangrene caused by the car crash that hospitalized him. The car crash, according to Peter's mother, was due to his father's alcoholism, something his father always denied: he said he didn't drink. Peter's father used to fall over a lot, he would fall down the stairs, fall over in the kitchen, just as Peter would come to do.

Christine explained to me that she and Peter suspected that in fact, a perceptive doctor had understood the real cause of the car accident, namely the illness that would eventually appear in Peter. She and Peter came to the conclusion that this doctor had offered Peter's father a way out, based on the circumstances before he died: the night prior to his death, Peter's father had had a special meal delivered, and he summoned family and friends to see him, and in the morning he was dead. Without attributing causal power to these prior events, I note simply the descriptive significance for Christine of contextualizing Peter's decision relative to their shared understanding of the nature of his father's death: that voluntarily ending life was considered a possible and reasonable way out, whose significance lies not only in the example it sets but also as a counterpoint to his mother's suffering during her death in hospital. Indeed, the more we talked, and the more I learned of Peter's character, the more that biography

and parameters of personal history appeared if not to “explain” his choice, at least to provide elements for accurately describing how such a voluntary death became “thinkable”.

Over the course of 2008 Peter’s symptoms began to get worse: “He used to ask, can you hold me up darling; can I hold your arm? And I would say of course, because, he’d say, ‘my right foot is dropping’. But of course, that’s the sign of motor neuron disease. And Peter became very studied in his walking, as did my father in law. And I think it was to make sure it didn’t drop, to try and control all that dropping. We got to the point where Peter was called in to the doctors and to the specialists, and was told he had motor neuron disease.” In March 2009, after several months of tests and second opinions, Peter received a diagnosis. Initially, Christine interacted with his doctors, relaying to her husband the likely interventions required, as he did not wish to discuss the disease further with his doctors. From the point of view of the doctors treating him they were looking ahead to the likely need for “PEG [*percutaneous endoscopic gastrostomy*] and non-invasive ventilation”. A doctor’s report indicates that Christine “should try and establish her husbands [sic] view on these possibilities in advance.” PEG and ventilation are required as the nervous system and muscle tone break down. Alongside the possible medical interventions, Peter was also contacted by a local occupational therapist, asking about whether they could help adapt Peter and Christine’s home to accommodate his likely needs given the probable course of the illness. The therapist reported in April that Peter did not wish to accept a visit from their team at that time. Moreover, “he expressed concern as to what anyone could do to help as he stated that his condition is not going to improve.”

In June 2009, however, Peter had a slight change of orientation: he contacted his doctor in order to ask whether occupational therapy services could make an assessment of what they could do for him. Moreover, his consultant ordered respiratory function tests in order to give a baseline figure to assess the need for future interventions regarding ventilation. In July Peter contacted the Medical Research Council (UK) Center for Regenerative Medicine. He thanked them for their most recent report and understood from their reply that whilst research continues, there was nothing to be done in terms of slowing or curing the illness.

Christine narrated how it was recommended that Peter read a long article about the illness and possible management strategies: “So, I read it from cover to cover and I thought this is going to be really really hard. And he read it. And at the back of it, it has also sorts of things and it says record your falls, record this, record that. And he read it and he dropped it in the bin. And I said “why did you do that? Don’t you want to fill out these things?” And he said “no, that’s decided it, I’m not staying to the end.” Peter contacted DIGNITAS in August 2009.

Peter had taken a decision. He started to arrange his death in August 2009 and he died by assisted suicide on 10 December 2010. It is noteworthy however how the decision was mediated and formed. On the one hand, he couldn’t and didn’t do it alone. In the first place it required a negotiation with the association itself in order for the request to be accepted. In the second place, Peter accepted to have his death filmed as part of an effort to prompt public and personal reflection of the question of assistance with suicide. Thirdly, observing the film shows how during the actual process of going to Switzerland and in the process of dying, the choice and its signification was being mediated and being formed along with those around him and in relation to him, principally his family. On the other hand we will see how for Peter being autonomous, to the degree possible, and being seen to be autonomous, was crucial to his self-understanding and his conduct.

Neutral

Let me note, before we enter the situation and steps toward a voluntary death, that Christine’s efforts to situate Peter’s choice to die within his family history and the prior event of his father’s death provides an impulse to resist taking at face value Peter’s own claim that his choice is “obvious”. The final section of this article will moreover offer a description of the gestures of dying which shows heterogeneous significations for an observer. Without undermining the fact that it was his choice, nevertheless the “obviousness” of the choice, and the self-evidence of its signification, can be investigated by approaching it with what Roland Barthes has called “the Neutral” (*le Neutre*) or “the desire for the Neutral” (*le désir du Neutre*): i.e. that which eludes or thwarts, or disrupts, a signifying or logical opposition (e.g. dignified/undignified). Arrangements of gesture, discourse, language, body and attitude

concerning choice and necessity, can be taken up “neutrally” as clusters of gestural activities rather than as whole compositions with all-encompassing “messages”, obvious ones, that could be summarized, neatly packaged and transmitted. I will follow Barthes in searching for a mood to grasp gestures and discourse in assisted suicide, one that is neutral in his sense of disrupting paradigmatically opposed terms, a manner of both observing and refusing to acquiesce to the obvious or imposed message of any narrative, gesture or act, and which primes a search for the ethical character of working through discordances and indeterminations. Barthes’ “desire for the Neutral” may aid us in understanding assisted suicide as a manner of ending living that is not quite death. *Exiting* life is not quite dying; the ending of life is not isomorphic with a search for death. Barthes grasps the point in trenchant terms: “It seems that in Death, what is essentially taboo is the passage, the threshold, “dying” itself; life and death are relatively classified states, which enter into paradigmatic opposition. Life and death are accommodated by meaning, which always pacifies; but the transition between the two states, or more exactly, as will be the case here, their *encroachment*, balks meaning, engenders horror: an antithesis, a classification is transgressed” (Barthes 1985: 275). The “Neutral” is therefore not the third term relative to a semantic opposition—life / death; hope/despair—but a second element in a sequence, that takes up a first element, namely the characterization of a form and experience of pragmatic and semiotic breakdown. We will explore such an endeavor, first as Peter chooses to die and then in the threshold of dying.

A scene of evaluation

The scene that follows is drawn from the documentary in which Peter agreed to appear, and serves as part of the available record of the process through which Peter’s decision was mediated. Let me clarify that, of course, I am aware that in basing this analysis of the process of Peter’s assisted suicide the object of my analysis has already been “staged” to the degree that, on the one hand, the film itself is an edited point of view on the process, and, on the other hand, what took place may have taken place differently were the camera not there. This latter point is important with respect to the analysis of the scene of dying.

Peter meets the doctor working with DIGNITAS in the hotel room where they are staying. In the film we see the doctor evaluate Peter's condition. She evaluates his physical capacity, such as whether he can get out of the chair by himself. She checks his psychological state. The viewer is unaware of the fact that Peter, by this time in December, is now mostly confined to a wheelchair, a support which never features in the film, according to Christine, because he didn't want to be seen to be so handicapped.

"Have you ever, ah, felt depressed during the time of your illness?"

"No, I'm not a depressed sort of person." Peter pauses and his gaze drops to the floor.

"I've, had mixed feelings about it, of course. But I wouldn't call it depression." The examination continues; the doctor checks whether Peter is able to hold a glass and whether he can swallow its contents unassisted.

"That's perfect. You will have no problem at all. I would like you to think about it again."

The following day, the doctor returns for the second examination which will establish whether Peter will receive the definite doctor's consent for the accompanied suicide to take place if he wishes to do so that day. She begins by making a general assessment of the problem of decision.

"When I see people with these illnesses, for me it is quite difficult to decide, is it the right time to go? If I say no, you have to go home. You can't die."

"Understood." Peter nods respectfully. "Yes, I understand what you are saying, and I ..."

The doctor continues "You are the only one who can decide which is the right moment. You are sure you want to do this?"

"Oh yes, I've always been quite convinced all the time."

"Have you been listening to yourself or have you been talking to your wife?"

"Oh no it's my own conclusions."

Christine intervenes. "If he were listening to me he'd stay at home for Christmas."

The doctor mediates. "It's amazing but it's much easier for the one who can go than for the ones who have to stay behind"

"Yes I understand that", Peter confirms.

“I obviously don’t want him to go so I feel that it is going to be tough on me, but I think it is going to be a great relief for you” Christine explains.

The doctor has provided a space in which Christine is integrated into the examination and Christine takes this invitation and redirects the focus of the conversation from her position and affect towards Peter. The doctor pushes the attention back to Christine, as third party, by focusing on Peter:

“She would like you to wait.”

“Yes.” Peter replies.

“Yes” the doctor says.

“Yes she would”, says Peter.

“I mean, Peter’s been my other half for forty years and it’s going to be a terrible wrench.”

“Yes.” Peter affirms, simply, tinged with pathos.

Aside from a clinical encounter

These sequences are far from classic scenes of “clinical encounter”: they take place in a hotel; they are the only two meetings the doctor and Peter will have: can we call him a patient and their relation that of the doctor to the patient? The medical doctor has, of course, read the formal request to DIGNITAS including personal letter, CV and medical reports and thus the doctor knows about Peter’s personal and medical situation. We see the indetermination in this relation expressed in the transformation from the first meeting to the second. The first thing we notice is how a medical category of “depression” mediates the possibility of a positive verdict for access to assisted suicide. The question is direct, as are the consequences of responding in the affirmative or the negative. If he were to say that he was depressed, this could be grounds for halting the motion towards an assisted suicide. We have no reason to doubt Peter’s response. It is rather the situation that is striking, the manner in which Peter’s thoughts about his illness are both solicited and qualified: having “mixed feelings” about having motor neuron disease is acceptable; being depressed about life with motor neuron disease would however be a reason to put in question a request for assistance with suicide.

In this first meeting we have thus a double check: is Peter depressed? Can he accomplish the act himself (drinking the lethal solution)? I.e. is he both reasonable *and* an agent. In the second meeting a new element is added, one that is not reducible to medical judgment or the question of rational agency: by whom and how can a judgment be made? Since the first meeting established medical authority, and thus the responsibility of the doctor for providing access to the drug and to ensure it can be taken by the person, in the second meeting medical authority, and responsibility, is downplayed.

The doctor says plainly that it is “difficult to decide” whether it is the right time for Peter to die. What she has done then in the first meeting, the previous day, is to establish the general possibility of assistance with suicide, reaffirming the medical diagnosis, determining that according to medical judgment he could end his life: meaning both that there is a reason and that he is able to, which then opens onto the indetermination about whether he should go ahead with his suicide. The sincerity and etiology of his request is tested against a medical category in order to qualify its reality. It is then up to Peter as to whether this day is the right day to die. The reality test of the request to die must be passed back to the requester: only the requester can decide.

The decision might seem to be obviously individual. It is worth observing, however, how the examination of Peter’s intention to be assisted in ending his life involves Christine, his wife. The doctor responsible for access to a prescription for a life ending dose of barbiturate, mediates—in a limited fashion—both Peter’s request to exit his illness and Christine’s expression of the wish that he stay home for Christmas. We see how Christine is integrated into the examination at the moment in which Peter’s sincerity is examined: “have you been listening to yourself or your wife?” the doctor asks. The coordinating conjunction “or” could be taken as a formulation crystalizing an abstract conception of personhood and freedom: *either* he is only listening to himself in which case he is an autonomous individual; *or* he is listening to his wife in which case his autonomy may be put in question by an external constraint—as he says, “oh no, it’s my own conclusions.”

The answer Peter gives is the official answer of an autonomous individual. The question solicited this response, and indeed it is confirmed as true. The question however also opens up a space in which his

“own conclusions” can be put in relation to a range of people and things: not least the care of Christine who confirms that he hasn’t been listening to her since she would like to him to wait until after Christmas. On the other hand, it is thanks to the love and support of Christine, both emotional and physical, that he could go ahead with his plan. The doctor’s careful mediation, Peter’s response and Christine’s intervention allows all three people to participate in the question of how Peter’s expressed wish has been forged and how a judgment can be made. Such participation among a triad of positions in the making of a judgment, and not only the taking of a decision or making of a choice, is clearly evoked in the series of statements that elicits Christine’s participation and elicits acknowledgment that her wish has been heard and her support recognized.

The decision, although ultimately attributed to Peter, is the result of the unfolding of a situation, not given in advance, for coming to the judgment that he can end his life, one that shows those present the range of *exterior things* with respect to which he is in relation: (i) his position as husband to his wife, (ii) his experience of illness, (iii) the clinical presentation of illness, (iv) its anticipated course, (v) the image he has of what the end of his illness looks like, (vi) Christmas, (vii) the loss that Christine will live with if he decides to go through with it.

Thinking the obvious

Peter and Christine arrive at the premises of DIGNITAS. They are met by two companions, one of whom is Erika, who takes the situation in hand. As Christine wrote to the association three weeks after Peter died, in response to their “feedback form”, from the moment Peter was greeted they felt assured. The companion excuses herself for the administrative paperwork they have to fill out and also that she will have to ask Peter at several points about his volition: “Are you sure you wish to die?” Erika asks him. He replies, “I feel that I have very little choice, in the grand design.” It is precisely this feeling of having “little choice” that can be qualified as neutral: the “little choice” ruffles the opposition of freedom and obligation: a neutralization of the discourses and demands to be either in favor or against or to be either sure or uncertain (and hence disqualified), or either scared or steadfast, etc. In Peter’s own terms, his

choice was “obvious” (it had a pacifying sense): dying with dignity was resolutely signifying, the consequence of volition and imposition. It is precisely this forcefulness that I think could be said to call for a neutral grasping. The meaning of the gesture, its imposing meaning is obvious, whereas Barthes’ “Neutral” is a manner of taking up the accompanying “obtuse” or “lateral” meaning. Obvious meaning is symbolic and “intentional,” as Barthes reminds us, “taken from a kind of common, general lexicon of symbols; it is a meaning which seeks me out, me the recipient of the message” (Barthes 1977: 34). The counterpoint to such meaning appears not in lieu of, but rather occasionally accompanies obvious meaning, not undoing such a meaning, but permitting a different grasp on the scene of observation.

In what follows I prime attention to the act of suicide as an activity, a gesture that is given a specific form, that enacts an obvious meaning and yet whose sense is not determinate. It is worth remembering that it is an uncommon practice. As a form of dying it is illegal in the vast majority of countries. As such attention must be given to what in literal terms this “assistance” looks like, in addition to the supports of medical evaluation and the care and place of those who are present in the making of the determination to die.

What follows is not to be taken as exemplary, but rather as an observation of a situation of dying that was captured in such a way that it could be revisited. From Peter’s point of view one purpose of rendering visible his death was to challenge the political constraints that exist in the UK around assistance with suicide. Paying attention to precisely what happened during the scene of dying, allows for a more fine grained characterization of the significations of the situation.

Gestures of dying

It should be remembered that the film, in addition to being a personal and ethical reflection for Pratchett, was also designed to intervene in a public debate in the UK about assisted dying: A way of dying that is relatively quick, usually taking less than forty minutes, as well as clean, the body usually remains integrated with no liquids or solids leaving the body. I stress that this is usually the case: there are however rare cases for there to be variations, such as it taking many hours for the person to transition from unconsciousness to death, or more rarely, complicated consequences if the person vomits the lethal

solution, despite the antiemetic routinely taken to prepare the body for the lethal dose of barbiturate prior to oral ingestion.

I have arranged three images (1, 2, 3) drawn and reworked from the documentary so as to emphasize the gestural motion that is presented, and through which I think it is possible to grasp both obvious and lateral significations in the scene by way of two terms for describing movement within the images: diastolic and systolic movement: I take the pair of terms “diastolic” and “systolic” from Georges Didi-Huberman’s article “Pathos et Praxis : Eisenstein contre Barthes”(2012), in which he identifies the specificity and originality of Russian filmmaker Sergei Eisenstein’s intervention into the movement of images by his use of a double, vital, rhythm, read principally through his 1925 film *Battleship Potemkin*. The terms take on both literal and symbolic dimensions. At a surface level, we are led to observe, from its etymological root, the diastolic movement of separation or expansion outwards, and reciprocally, with systolic movement, we are led to observe contraction, or closing in. Accompanying the observation of these literal movements are the iconographic resonances that can be identified. The identification of movements in these images can be formally connected to iconographic gestures of lamentation and compassion, a connection that aids us in observing the form given to such a visceral experience: a form for pathos.¹⁰

There is an initial diastolic movement in image (1) in which the effect of the barbiturate takes hold in Peter’s body. He gasps. He is held by the accompanier, Erika, who pulls Peter towards her in symmetric opposition to the gesture through which Christine turns away from him. Erika is containing Peter as Christine (to the left of the image) contains herself and pulls away: Erika has a tissue placed under Peter’s mouth just as Christine covers her own mouth with a tissue. This first movement, which is short and dynamic is then contained and followed by a systolic movement (2) in which the configuration narrows

¹⁰ Pathos is of course both a medical and theatrical term (Rabinow 1989: 13), as well as an art historical term, used most powerful by Aby Warburg to trace within Renaissance painting and sculpture the “afterlives” of ancient Greek forms for pathos. Warburg provides an historicizing approach to repetitions, differences and variations in the forms that can be given to express visceral experience of breakdown. Crucially Warburg identifies gestural motion as the key site for the observation of such “formulas of pathos” (*Pathosformeln*). Moreover he pushes us to track the “survival” (*Nachleben*) of earlier elements of motion in later formulas, showing longer durational configurations and reconfigurations of these forms (Didi-Huberman 2002).

and closes in, as Christine turns to hold Peter and Erika holds his head. He is doubly embraced. Erika and Peter hold a tissue together, whilst Christine no longer holds hers to her mouth. Finally (3), Peter has now lost consciousness, Erika is explaining in clear terms to Christine what is happening to his body and that he will soon die. In image (3) we see the entourage move to an upright position, as Peter's posture is now supported by an airplane pillow put around his neck by Erika. The viewer now sees Pratchett for the first time since the sequence began, looking on. No one holds any tissues, although the box is placed close by in case. A calm has taken hold as they wait for Peter to die.

Christine's memory of this sequence was twofold: her initial effort to keep control as Peter gasped, and then of Erika walking over to the door and opening it as the snow fell, with cold air streaming in, so as to let Peter's spirit out.

Observing these scenes makes for difficult viewing. Most people today die in hospital or care homes. The last day of life in hospital often means supporting the body with the assistance of medications delivered through tubes, as the person lies on their back or side, assisting vital functions to slowly break down. In the course of many different forms of dying, there are gestures of care and compassion, by loved ones and medical staff. Image 4 is an important counterpoint drawn from Frederick Wiseman's incredible observation of the intensive care unit at the Boston Beth Israel Hospital in 1989: an elderly woman has been transferred to the intensive care unit and will shortly die. Her son, who wanted her to receive "everything" in terms of treatment, endeavored to make it to the hospital from Chicago. He doesn't make it in time. The doctors have discussed what is reasonable in terms of treatments, given her intubated and semi-conscious state and given her son's wish. She is visited by Rabbi Bard, who tells her that she is not alone and that they are there for her. The nurse was with her as she died. Assisted suicide practices, as those within and outside of the associations all insist, of course, do not have a monopoly on "dignity" or on "compassion".

Nevertheless, observing Peter's death allows us to specify several aspects of its meaning in this particular situation: he was sitting upright. The posture has a functional as well as overtly symbolic dimension: functionally speaking, in order to prepare the body an anti-emetic is taken, before oral

ingestions of the barbiturate. The risk of vomiting is high due to the fact that Natrium [Na] (Sodium) Pentobarbital is alkaline and has a bitter, unpleasant taste, and in its concentration (15 grams dissolved in a small quantity of tap water) can lead to nausea. The upright posture helps the barbiturate to flow more easily into the stomach and to minimize the likelihood of vomiting. Vomiting is a very rare occurrence which can cause major problems, such as the person falling into coma and not dying, but rather waking up again after many hours if not days. Secondly, there is the symbolic character of the position: a doctor, who is both a palliative care specialist and assisted suicide accompanier, described to me how she and other accompaniers, consider the posture to be more “dignified”.¹¹ Gesturally, assisted suicide provides something specific: the possibility of dying in a position and manner that adherents qualify as “dignified”, including the possibility (frequently the case during my fieldwork, of actually being held during dying). The specific manner in which Peter is held and holds himself configures the symbolism of dignity (upright) with the gestural index of compassion and lamentation (image 5, Giotto’s *Lamentation* c 1305-6), heads tilted toward and touching one another. Beyond the specificity of the configuration of Peter, Christine and Erika, the form of this held death, from the accounts of accompaniers and family members with whom I have spoken, and in the situations in which I have been present, is often composed of the holding of the head, hands and/or feet. Such a form partakes partially of a long durational gestural survival: that of compassion and lamentation. One sees a gestural resonance in the *Lamentation*, which should be grasped “Neutrally”, as non-isomorphic (neither identical nor opposed) in terms of signification.

We can contrast the scene of leaving life, with its compositional signifying elements of both dignity and tenderness, with a scene of medical compassion, of the saving of his life portrayed by Goya in 1820 (image 6). Rather than the held death of image (2), with postures and faces turned to one another, we have

¹¹ Silvan Luley, of DIGNITAS, underscores that from their point of view, at DIGNITAS, “the upright position is really for practical reasons: 1) a person lying flat on his back cannot really drink from a beaker, let alone swallow liquid easily; 2) in the upright position, the liquid “runs down the esophagus into the stomach” easier; 3) communication / eye contact with all the people in the room (accompanier and relatives/friends) is easier; 4) the person has “an outlook” and does not just stare at the ceiling.... Some DIGNITAS -members confined to a wheelchair choose to ingest the medication sitting in their wheelchair - weather conditions allowing it, some outside in the garden.” – Email communication. Anthropologically speaking, it seems pertinent to consider the accompanying significations, even of “practical reasons”.

here Dr. Arrieta embodying the care and vital quickness of early nineteenth-century medical practice: rallying the sum of forces resisting death, imposing remedy as the patient, ready to acquiesce to fate, turns away.

Assisted suicide partakes of these long durational gestural survivals, of lamentation and compassion, and is yet equivocal, in two key respects: on the one hand, as described above, the systolic motion is the second phase in a movement in which the trio is first split, the composition opening outward and away from the center. The second movement then closes in around the body, as in the core iconographical gesture of lamentation, to then open upward, to an upright, neutral, position as the body holds itself. This third, last, phase is crucial for ongoing indetermination of any possible judgment—judgment in the sense of the attribution of a mode of being to the scene, and not attribution of one side of a binary value: lamentation in Christian iconography has as its ethical end a state of redemption, just as Arrieta's compassion had its end oriented to cure. Peter's final posture, in the sequence of dying, is oblique to these salvational stakes.

Regardless, he escaped.



Image 1. Erika holds Peter after he ingests the lethal dose of barbiturate. Christine composes herself. Photo from Charlie Russell's film *TERRY PRATCHETT: CHOOSING TO DIE* © 2011 Keo Films.



Image 2. Christine and Erika close in to hold Peter together as he begins to lose consciousness. Photo from Charlie Russell's film *TERRY PRATCHETT: CHOOSING TO DIE* © 2011 Keo Films.



Image 3. Peter has lost consciousness. Erika explains the physiological process of death. Erika and Christine sit upright and the camera zooms out to reveal Terry Pratchett, observing the scene of dying. Photo from Charlie Russell's film *TERRY PRATCHETT: CHOOSING TO DIE* © 2011 Keo Films.



Image 4: Nurse and dying patient in ICU of the hospital. Photo from Frederick Wiseman's film *NEAR DEATH* © 1989 Exit Films, Inc. All Rights Reserved



Image 5: Giotto di Bondone Scrovegni 1306. Lamento (Il Compianto di Cristo). Fresco, (Arena) Chapel, Padua, Italy.

Source: [https://upload.wikimedia.org/wikipedia/commons/3/3a/Giotto - Scrovegni - -36- - Lamentation \(The Mourning of Christ\) adj.jpg](https://upload.wikimedia.org/wikipedia/commons/3/3a/Giotto_-_Scrovegni_-_36_-_Lamentation_(The_Mourning_of_Christ)_adj.jpg)



Image 6: Goya, Francisco, 1820. *Goya asistieron por el doctor Arrieta*. Oil on canvas. Minneapolis Institute of Art, Minnesota

Source: https://upload.wikimedia.org/wikipedia/commons/d/d6/Self-portrait_with_Dr_Arrieta_by_Francisco_de_Goya.jpg

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