

A STATEMENT OF BELIEF:
“DEATH WITH DIGNITY” BEGINS AT HOME

(Living Wills ‘versus’ Euthanasia and Assisted Suicide
– a false dichotomy)

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BRIEF to the COMMITTEES SECRETARIAT of the SELECT
COMMITTEE on DYING WITH DIGNITY –

A PERSONAL MANIFESTO

In an attempt to lend voice to the movement to liberalize Quebec's (and indeed all Canada's) policies regarding an individual's prerogative to end his or her life when the appropriate time has come, I submit this personal testimonial. It is written in the spirit of protest against what this writer considers an inhumane esprit de corps governing the mindset of many well-meaning people, and is therefore a partisan, even militant, statement of advocacy for euthanasia and assisted suicide, nothing more, nothing less.

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Statement

I may be considered heretical for thinking as I do, but I strongly believe in the right of any individual, at any time, for any reason, to end his or her own life if he or she feels it to be unbearable. I do not believe that anyone else has the insight, and hence the authority, to define what "unbearable" is for another. Also, because of the stigma associated with it, I do not like to use the term "suicide" for this act of personal will, preferring to think of it as "self-finalization." (This is not a euphemism, but rather an expression of my atheistic conviction that this life is the only one each of us has.) I further believe that, if self-finalization is for some reason not possible, and one's own life is felt to be *physically* unbearable, then the person wishing to die ought to be assisted and helped to this end. I do not believe that this is murder. Finally, in the same way that self-entrepreneurship in life is seen as a virtue, so, with regard to contemplating and finding benign ways to finalize one's life I feel that a similar resourcefulness ought to be encouraged by our society well before death, so that death is not left unexamined until there comes the pressing and oppressive necessity to do so.

I have watched someone I loved – my own father – decline from disease to the point where he no longer wanted to live. Though he had a hunger for life prior to his illness, and worked inventively with his cancer, studying it as best a lay person with a scientific background could, he eventually reached a point where he had had enough. He died a horribly un-restful death, frightened and bewildered virtually to the end. This was not "death with dignity," although he did die in his own bed at home, and by his own decision.

I believe that his dying did not have to happen as it did. I believe that it could have been greatly eased and his psychological distress greatly ameliorated had the medico-

legal paradigms of the society in which he lived allowed him openly to state to his doctors and their staff his intention to finalize his life through fasting and dehydration. Were this an ethically admissible response to being terminally ill in that time and place, he would likely have been informed by professionals as to how to go about it safely and with minimal distress. Had he been encouraged to discuss this choice with friends and family he would have had their frank support and participation as well. But, to protect and indemnify them, he felt beholden not to speak of his intentions openly and directly, and thus did not seek their help in planning and effecting a truly benign end – which is what, anecdotally, he had heard death by starvation and dehydration is supposed to be.

Because this society criminalizes as “suicide” all intentional acts of self-finalization regardless of the context, contingencies, mitigating factors and sheer existential invalidity, which in many cases make such an act of self - [de]termination both ethical and merciful as well as appropriate, my father was unable openly to reveal to *anyone* (except his two children, and then with the injunction that it remain in our confidence) that his refusal of food and liquid was a conscious and elective act. The home health aides didn’t know of it. The doctors didn’t know of it. However, *had* he been able to tell others of his brave decision, the entire tenor of his last days might well have been substantially different. For then, because he remained to his last a healthily inquisitive man, he would for certain have become better informed as to the necessary prerequisites and steps to be taken in order to make this mode of self-finalization something other than the ferocious torture-by-thirst-and-desiccation which it in fact became.

The data are out there. The doctors might have been able to offer him empirical information about the biological consequences of this course of action, possibly recommending a schedule of abatement or offering a pharmaceutical means of alleviating the symptoms, providing him with minimal intervention in order to ease his transition to his final, pain-free state. Or, they might have advised him upon another course of final action altogether. In short, both medical and psychological comfort might have been afforded him, but were not, because he had to hide his “suicide” – (this eighty year old man who weighed ninety-six pounds and struggled ineffectually to hack up his bloody mucus, and was barely able to stand upright, unassisted) – from the world. After he lay down for the last time, it took him eight days to die.

I do not wish to die as my father did, wanting release, but for far too long, not being able to attain it. Because “legally assisted suicide” is illegal in this province and this country, those who love me and would want to help me not to suffer shall have their hands tied if and when it comes to the point where I require assistance in my own self-finalization. I could not expect them to subject themselves to the legal consequences if they did help, and asking them to take me to a country where such mercy is legally granted is asking too much. If I am able, I shall see to it myself that things do not progress to the point where a merciful assistance would then be needed. I have been sick with cancer four times in my fifty-two years, and have prepared myself over and over ... and over again for the worst. No other human being has “walked” my exact “walk,” and hence no other human being is qualified to “talk” to me *my* “talk.” Neither you, nor the person sitting next to you, has gone through the same emotional and intellectual processes I have since my first confrontation with death at age twenty-eight, and so neither of you have the intimacy, can know what it feels like for me to have received my present diagnosis and prognosis in yet one more struggle to regain biological homeostasis and spiritual equilibrium. You can’t. And therefore you mustn’t try to. You simply haven’t the qualification. *For, you are not me.*

Living Wills, As Against the Right-To-Self-Finalization

Here is where the notion of the “Living Will” comes into play. Intended as an entirely sui-generis document for ratifying a person’s desire to die “*naturally*,” in fact the Living Will is inextricably related to the lawmakers’ tacit ethical construal of death by euthanasia or assisted suicide as “*artificial*.” But what is a “natural” death, and what an “un-natural” one? Has the perceived “*artificiality*” of euthanasia or assisted suicide perhaps to do with the amount of *initiative* these modes of finalization invest in the *individual*? Is this (like the misguided “‘Right-to-Life’ versus ‘Right-to-Choose’ abortion ‘debate’” in the States) what makes some policy-makers restless, makes them feel that an individual hasn’t the right to take the initiative in deciding the time and place and means of his or her own death without the approbation of society’s other citizens? If a *plurality*

of others passively sanctions the death-inducing act of refusing or withdrawing medical intervention, does this make it more of a “natural” death? I do not think so. If we renamed the Living Will a “Default Death Directive,” because it operates in default of a person’s own physical initiative: in other words, *because she cannot*, the terminal person *does not* withdraw her own tubes - would this result in her total passivity being seen as *more or less* artificial? The minions may bless a document to which I may once have appended my signature, but this, surely, ought not to make my death be deemed any more “natural” and hence more acceptable, should it? Because of the inevitable interlacing between these two concepts, it is perhaps useful, therefore, if we examine this inter-connection between Living Wills and facilitated self-finalization in greater depth here.

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If, for reasons of temperament or circumstance, I am unable, intentionally, to ease myself into my own death, and merciful intervention by others is disallowed, then I shall have to resort to the approach governed by the more conservative, less pro-active, and hence, in my view, insufficient concepts and options contained in a “Living Will” or “Advance Directive.”*

If such is the case, I shall have to allow that others who do not know or love me will be given the power to adjudicate my finalization per the instructions contained within that dubious legal document. I have put my signature to a Living Will (or “Advance Directive” as it is referred to by the Montreal Jewish General Hospital,) but have done so under protest, knowing that my physical and mental decline, with the attendant distress that accompanies this downward progression, may as a result be, like my father’s, needlessly prolonged.

Prolonged, that is, to the point where hyper-medicalization may no doubt creep steadily and imperceptibly in, so that, before *anyone* is aware of it, decisions such as are itemized in this Advance Directive – e.g., whether or not to administer CPR, or TPN with

* And by the way, in Quebec, even this legal instrument, designed to express “in absentia,” the will of a dying person who is unable to articulate his or her current views about staying alive, is often found to be ineffective, frequently coming in conflict with the obdurate decisions and *pro forma* methods of doctors responding automatically to critical end-of-life issues. I have heard of too many cases where a patient’s wishes were superannuated or overridden in the drama of rescuing them from a grave medical emergency. The words of the patient who has written and signed his or her Living Will are then about as audible as the voice of reason coming from some rational person arguing during a stampede that it is far safer to proceed in an orderly manner than to make a rush for it.

intubation, or to proceed with a blood transfusion or IV antibiotics – come, at the eleventh hour, to be addressed. But by then, I maintain, *it is too late* for “death with dignity,” which is what Living Wills profess to offer. Too late, at least for those of us for whom the shock of the unfamiliar is felt to be undermining: Who among us – (except perhaps ER personnel who deal with such dramas daily, and even they, not likely, when they are on the receiving end of the care) – *who*, I ask, would *not* be undermined by all those bizarre gadgets and interventions employed to salvage what is unsalvageable? Yes, a life may be prolonged, and thus “saved” thereby, but what is *un*-salvageable is, in the end, our indefinable - but *not inalienable* - personal sense of what is an acceptable boundary for normalcy and intimacy, beyond which others must not trespass.

Since all the medical brouhaha that encumbers serious illness and morbidity in North American hospitals is kept intentionally and rigorously separate from our private lives, the damage to a seldom- or never-hospitalized, formerly healthy person’s psyche by this often novel disruption and commotion, suddenly, at the end of life – (perhaps *even* if he or she is insentient) – is incalculable. Meaning, that it is beyond empirical assessment. Researchers just don’t know. And because they don’t know, they haven’t the right to presume to be able to gauge our alienation thresholds and decide for each of us what our tolerable limits to such radical intrusions are, beyond which we crack and become spiritually dehumanized. Gravely ill people don’t tend to speak up for themselves. And I am not, here, even taking into consideration the similar or equivalent effects upon the family and loved ones who get to be the hapless audience for such dramas, and who, like the sick, are often too overwhelmed or disaffected to say: “*enough!*” We need to create a climate in which the timid, the frightened and the discouraged will feel able to say this word if they want to, openly and unashamedly, *well before* the ambulance comes to take them away. Which is what would happen more and more if we began to accept death as a part of life and made euthanasia and assisted suicide viable alternatives.

Furthermore, I hold that when a person’s life reaches the stage of physical dissolution where it requires a litigious document to protect all parties potentially involved with that person’s impending death from responsibility – and yet this same document issues from an institutional mandate which simultaneously deprives this person of the legal right to take the responsibility for his or her own death into his or her *own*

hands – then things have attained a level of absurdity (read: “we’ll let you let *us* kill you, but we won’t let *you* kill *yourself*”) and proceeded beyond logic and become ideology. And ideology is about as far as one can get from the intimate. By then, the professed goals of “comfort” and “dignity” have become little more than hypothetical and wistfully posed platitudes, un-germane to the terrifying realities being experienced by the one dying and by those who love this person.

The whole issue is very complex, and I am not insensible to the concerns raised by others that legalization of euthanasia and assisted suicide can open gateways to abuse and discrimination; whether it be through family members seeking personal gain by “cleaning up house,” or through mass genocidal initiatives against ethnic, handicapped or gender-alterative “Undesirables,” as it did in Nazi Germany and elsewhere. But while, as a Jew who knows history, I do not categorically dismiss the possibility of this happening in “ideology-crazed” North America, I *do* observe that the need for euthanasia and assisted suicide, here, today, so outweighs any immediate probabilities of abuse, as well as perceived benefits from the current prohibition, that I take the strenuously partisan position I do in hopes of correcting the polemical imbalance that exists.

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If euthanasia and assisted suicide were operative in Quebec today, I would not have the issue I do with Living Wills. It’s not that the Living Will, as a tool, is inappropriate once the time comes for it to be used. It’s that, like an introduced species that takes over a garden, it crowds out the incentive to reflect soberly about death in an indigenously personal way. A Living Will makes one passive the way canned entertainment does – once you have your iPod, you’re less inclined to learn an instrument, sing to yourself, create your own music. So too, when a legal instrument “does it all for you,” you stop thinking responsibly and creatively for yourself.

Put another way, when I sign a Living Will to ensure that my expressed desire not to be medicalized-(*literally*)-to-death shall be heeded, I am signing away my own theoretical freedom to choose the manner, the time, and the circumstance of my own death, ceding it instead to an impersonal institutional Authority comprised of The Healthy. My future power of will as a sick person has then been forfeited, conceptually, and been replaced by a depersonalized and official mandate that steps in to institute my

ostensible will as pre-determined by my selection of medical interventions I would disallow for myself from a liberal list of options. Yet what if, once I'm finally "there," I'm sentient but do not have the wherewithal to assess and articulate and modify the choices I made, back when I was one of The Healthy? In this case, my very own check marks on the page of the Living Will may become my own worst enemy!

Don't get me wrong. I believe we need Living Wills as long as we are the "Davids" against the "Goliath" of present-day Quebec's over-burdened, institutionalized medical system; the "One" against the "Many." In this over-medicalized society, the benevolent purpose underlying the establishment, as well as the sheer usefulness, of the Living Will menu ought not to be minimized. However, it makes no sense to have that "Goliath" be spelling out what the options are for a dying individual. If I am comatose or insentient, this is inevitable, and such a document is certainly better than nothing. But something is, I maintain, still wrong with even this scenario. Because, it is the very invitation to *prepare, beforehand*, for such a contingency *by responding to that menu of options* – exactly what a Living Will offers – that is unfair for it seduces me into feeling secure, thinking that, because I have checked off each of the boxes indicated, I may never have to contemplate my self-finalization, to exercise my right to conceive of and, if necessary, prosecute my own death. This is why I am against all such institutional menus.

What are the alternatives? To be honest, I am not sure. As I hope I have demonstrated, Living Wills are kind of like the "poor man's version" of the "Right to Die" ethos. It's the equivalent difference between, on the one hand, volunteering in a local soup kitchen and, on the other hand, lobbying for a robust, federally funded food assistance program. I know this sounds counterintuitive, even oxymoronic - and it is. It's asking the federal / (or provincial) government to think "local," to find a way of *federally* / (or *provincially*) fostering *local* intimacy, or in other words, legislating for people to have their peers, people they know and love and trust, and not just polite, paid employees to help them when they are ready to die.

How to do this seemingly impossible thing? One might as well try to get the Prime Minister to baby-sit one's two-year-old for an evening! I know it is not simple, but it will have to happen by means of a new paradigm that not just tolerates, but actually welcomes

alterative thought. I am not able to purpose here a list of creative alternatives. But what I can offer is this. That the *tone* of the medical intervention must be the opposite of the ubiquitous professional one used in virtually every medical establishment today. When I speak of “tone” I am really speaking about something more than style. I am talking about what it means to an individual in an ontological sense to be a part of the living world. Thus, I strongly feel that, if a patient shows the motivation, he or she ought to be encouraged to engage that essence of self-awareness, which is the realization of one’s mortality, by being encouraged to create his or her own menu or even dispense with such a list altogether, when considering how to leave this world. My father was a very proud man. I think it must have meant a great deal to him to be able to scrap the list and *choose* his day to begin dying. I, myself, can’t even imagine the fortitude it must have taken to sit down to, let alone eat, his last meal as he did that night in April 2000. Yet, in 2000, there was no one forthcoming from the medical world for my father to sit down with and talk, and explain his strange sort of dignity through proud self-discipline. And that’s a shame.

“Do not go gentle into that ‘Goodnight’ ”

Not everybody is so independent minded, it is true. And not everyone will feel, as my father apparently did, that they must make their own personal decisions about end-of-life outcomes. For example, the Deeply Religious seem to have a way of explaining, and so, coming to terms with their deaths with less angst or anomie, more calm and reconciliation, than your typical atheist. And the faith to which they adhere usually provides them and their religious community reassuring mechanisms for being “reabsorbed” back into whatever notion of eternity their belief system allows. But what about the majority of people who are only nominally religious, or even irreligious? Where do *we* – for whom the comfort of a “Sweet Hereafter” is not necessarily apparent – fit in? Don’t *we* deserve *our* equivalent of that sense of peace and resolution which the Deeply Religious ostensibly have – (which sense, I argue, the act of reflecting upon, and articulating one’s own thoughts about end-of-life outcomes can help to provide)?

I, myself, have written out sixteen pages of “Addenda” to accompany my Living Will, in order to make sure that my often idiosyncratic wishes regarding what I would and would not like to occur during my dying and after my death are explicit and

unambiguous. For instance, the Advance Directive I signed provides two boxes to choose from with regard to location: check off box ‘one,’ and you indicate a preference to die at home; check off box ‘two,’ and you indicate no special preference. However, because nature for me replaces the concept of “divinity” and has been essential to my feeling of wellbeing for all my life, I have requested that I be taken into nature to die, if that is possible. I further stipulate how, and at what point this should be done. But how many people are likely to feel free thus to amplify upon or modify the menu handed to them? Not many, I venture, when the esprit de corps runs against such independence of mind.

It may be hard for policy-makers to comprehend this fierce point of view, choosing to see it perhaps as a form of mere rebelliousness against a responsibly forward-looking system of social welfare. Sure, there will always be a good number of people for whom the Palliative Care Unit will be a reassuring prospect, and they deserve to have these – and *decent* ones – waiting in readiness for them. But what *I* find hard to imagine is that these same policy-makers choose, also, not to reflect on what the tremendous work of dying means, and how a terminally ill person risks becoming terminally *alienated* from his or her own body’s attempt at understanding this final labor by encountering those last moments in a hospital setting. Also, I call into question the notion that what we have at present is social “*welfare*,” if it attempts to adjust people to this eventuality. Until we have provision for assisted suicide and euthanasia *built into* our Living Wills, we do not have social *well-fare*. We have social *giving-up*. This, to me, is “lifeless” death.

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To assist the individual nearing the end of life, we need a new class of “un-professionals,” culled not from the ranks of social workers or medical ethicists, or even trained volunteers, with their uniforms and officializing badges – many of whom (I know from personal experience) are wonderfully attuned and sensitive people – but from the ranks of the now-recovered once-grief-stricken survivors, the chronically infirm, the medical “refusniks” who have chosen to “opt out” – – in short, those who are far better equipped to guess at, and translate for those near and dear into the language of the soul the intuitions, the fears, and the failures of heart of those close to death; to advocate for the dying, from an affective, not statistical perspective; to make bearable for their loved ones the finality of the doctor’s words: “There’s nothing more we can do.” We don’t need

more support groups for the bereaved, *more* trained palliative care providers (although their accumulated wisdom and skills are precious); we need more incidences of spontaneous, unsolicited, “unauthorized” conversations springing up in hospital waiting rooms between people poking their noses into each others’ affairs out of sheer empathy and interest. There really are as many alternatives to institutionalization as there are caring people out there practicing random, not rehearsed, acts of kindness. We need to begin to introduce a belief in, a trust of, and an ear for the experiences of the patients.

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Lessons From “Out There”: Schools and Prisons

As it goes for the hospitalized patient, so it goes for so many other sectors of the population. There is a remove between the “expertise” of the service provider (be that the warden, the teacher or the nurse) and the subjective knowledge of the recipient (be that the student, the prisoner, or the patient.) Some feel that using standardized quantifying indices such as Scholastic Aptitude Tests and IQ scores in schools accurately measures true “intelligence,” failing to recognize that a child’s *real* intellectual capacity is based in untold subtle and *qualitative* factors far beyond the reach of a multiple choice exam.

Others like believing in the “science” of criminology and in those “experts” the criminologists, instead of listening to and trusting prisoners themselves who, alone, are the best equipped to discourse on and describe their actually lived conditions, and hence are the best qualified, potentially, to un-alienate both mutually fearful and suspicious populations – the prisoners and society’s law-abiding civilians – one from the other. My analogy to patients is not inapt. Patients’ Rights and Prisoners’ Rights advocates both exist due to a similar need: to hear the voice of experience. Only when we really hear and attend to the voices of the incarcerated will society’s fears and zeal for *mythologizing* and *marginalizing* and *segregating* the prisoner be addressed. Only then will The Imprisoned come truly to understand the meaning of their past wrongful actions and find a way back to social health and acceptance.

Similarly, “Death With Dignity” can only come about if there is a concomitant acceptance and understanding, which, itself, can only be had through self-awareness, so long as a sick person is conscious and capable of such, *and allowed it*. Why wait until it

is too late? For me, the alternatives are simple, though daunting. My own “prescription” would be something of this order:

- To induce The Healthy to stop marginalizing The Ill, and to give the latter center stage by providing incentives and encouraging institutions to publicize (!) patients’ narratives of dissatisfaction and refusal of medicalization in open forums on the issue;
- To prohibit medical advertising and infomercials which mythologize Western notions of “healthiness” (whatever that is), implicitly glorifying youthfulness thereby, and, instead, start taking cues from the rest of the world in which sickness is seen as the rule, not the exception;
- and, To oblige our medical institutions (analogous to our prisons) to stop isolating the dying from the rest of society and begin considering the dying worthy of all the comforts which are not afforded them in these places.

We *all* get “there.” No one escapes Death, or has the privilege of legislating “His Majesty’s” behavior. At least - - no one who does, lives to tell of it. We need, each of us, to sit down with our own impending death before “that time” comes and have a real, honest talk with it. Simply that.

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Who, in the end, except I myself, can say when my own life has become untenable? If “Live and Let Live” is a desirable policy to uphold in life, then “Live but Let Die” should become the universally desired *quod surnam bonam* of all who, while healthy, have the wherewithal to contemplate their own deaths. The Governments of Quebec and Canada, which ostensibly so prize multiculturalism, must also learn to apply their pluralistic standards of lenience to the diversity of narratives of pain and suffering that eventually shall no doubt include even the most unimpeachably sanguine and robust member of parliament. If he, (and far too many parliamentarians are “he”s) let him not rule against that time when he himself will want to benefit from that leniency. Let him not be forced to live afflicted with the tragedy of his own intransigence. Let him vote in favor of what the Committee on Dying With Dignity refers to as “assisted suicide” and in favor of euthanasia in this province, so that, unlike so many patients today, he may at *his* end say, “there, but for the grace of my MP and my MD, go I.” And, finally – Dear Government – let this be in *my* lifetime! Amen, and Thank You.