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Mackenzie, Robin (2009) Reframing the Good Death: Enhancing choice in dying, neuroscience, end of life research and the potential of psychedelics in palliative care. In: Freeman, Michael and Goodenough, Oliver R., eds. Law, Mind and Brain. Medical Law and Ethics . Ashgate Publishing, Aldershot, UK, pp. 239-266. ISBN 978-0-7546-7013-1.

### DOI

### Link to record in KAR

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# Reframing the Good Death: Enhancing choice in dying, neuroscience, end of life research and the potential of psychedelics in palliative care

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Book Section in: Freeman, M, (eds). Law and the Brain. Ashgate Publishing, London, UK 2007

## Not Published Version

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**Abstract:** n/a

**Keywords:** n/a

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### Introduction

What is a good death? I will suggest that there are ways in which we could dispel some of the uncertainties which prevent our answering this question with more specificity. While what happens after death remains, and seems likely to remain, contentious, research into the neuroscience of the dying brain offers us the potential to enhance choice in death by enhancing dying. So far, this constitutes unknown territory. Our knowledge of the neurochemistry of various brain states is growing (Johnson 2004), but does not yet include an evidence base which would enable us to orchestrate our dying from this perspective. Whereas palliative care research has isolated factors associated with our feeling more comfortable about the dying process, like a belief that our life has had meaning and relief from physical suffering (Woodruff 1999), technologies which would enable us to chart the subjective experiences of dying have, until now, been unavailable. Brain imaging tools which measure neurological activity associated with moods, emotions and bodily processes now afford neuroscientists with the means to measure, record and compare sufficient varying subjective experiences of dying to establish an evidence base. Research on how specific substances and processes impact upon and determine subjective experiences of dying could thus provide a foundation from which choices over how our dying might be enhanced could be offered. This piece will explore some of the legal and ethical issues associated with such a quest.

An important initial caveat is that this modest proposal does not imply a fixed position in relation to ongoing social negotiations over how far we should permit medically assisted dying, the legalisation of unlawful psychoactive substances or human genetic enhancement. As I shall argue, ethical and legal justification may be found within aspects of current palliative care, the clinician's obligation of beneficence and many spiritual practices. Hence research into the neuroscience of

dying should be undertaken in order to enable us to choreograph our deaths in this way.

### **End of life research: the need for an evidence base to enhance choice in dying**

How far those who are about to die might become the subjects of research into end of life treatments, palliative care options or various characterisations of the good death remains contentious. Ethical approval of research involving the dying or the terminally ill hinges upon interpretations of legal criteria which seek to offer protection to groups of categorised as vulnerable. Those who are seen as inherently lacking in capacity, such as children and the mentally infirm, may lawfully become research subjects only where stringent ethical and legal protections are in place. These commonly centre about normative judgements over consent and capacity, assessments of risk, harm and benefit, and issues associated with decisions being made by third parties on the behalf of those seen as unable to do so for themselves.

End of life research on human subjects has characteristics which compound these complexities. As we embark upon the final portion of our earthly lives, many of us are in a state of poor physical health, mirrored in declining or fluctuating mental powers. The terminally ill are likely to be receiving medical treatment to ameliorate symptoms, control pain and preserve life until only palliative care is seen as clinically appropriate. Both side effects of treatment and the inherent characteristics of the dying process render end of life research problematic. Symptoms we may experience include breathlessness, nausea and vomiting, loss of appetite, depression, constipation, anxiety, nervous tremors, pain, confusion, weakness and various degrees of dementia. Treatments for one of these, such as the use of opiate-based analgesics for pain, typically impact upon others, as in engendering constipation or affecting alertness. Hence our ability to participate in research, or to agree to do so, is likely to be inherently compromised. It may be hampered by an inability to communicate, through the adverse effects of pain, disease and multiple medications or by the dying process itself. We are unlikely to have discussed research participation should we become incompetent with our families (Bravo 2003) and those who may make decisions on our behalf are unlikely to be able to assess our views on research participation should we lose capacity with complete accuracy (Kim and Kiebutz 2006; Stocking 2006). Finally, should we, towards the end of our lives, become research subjects, there is a significant likelihood that we will die before the project is complete.

In addition, while iatrogenic multifactorial confounding factors such as the side effects and mutual interactions of medications render assessing the effects of alternative treatments difficult, placebo trials present specific ethical difficulties (Hardy 2001; Kirkham and Abel 2001). Understandably, then, what end of life research there is has tended to focus upon symptomatic relief, disease specific treatments or palliative care. One of the consequences of this is that we know comparatively little about subjective experiences of the dying process in itself, or neurochemical activities which take place in the brain at end of life. Without the

evidence base customary amongst most areas of clinical treatment, the ability of clinicians to evaluate alternative means of providing appropriate care for the dying is compromised.

Thus, in an important sense, when we die we do so without an appreciation of choices we might exercise here. My suggestion in this piece is that the current debate over how far it might be seen as ethically and legally permissible to request hastened death as part of medical treatment has artificially restricted perceived possibilities. The resulting binary opposition between palliative care and medical assistance to die thus constrains unduly our choices over our dying. On this basis, I will put forward the argument that current developments in neuroscience demonstrate the potential to enhance choice in dying through the option of enhancing the dying process. For reasons of space, I will focus only on the potential of psychedelics to enhance our dying through enhancing our ability to find meaning in our lives. In order to support this position, I will consider the legal and ethical factors associated with end of life research upon human subjects, arguing that this may be justified within appropriate safeguards. The potential of neuroscience to ameliorate some of the previous difficulties associated with such endeavours will be explored as a preliminary to demonstrating how enhanced choice in the experience of dying might be afforded.

### **Neuroscience and end of life research**

Advances in medicine have given rise to situations where clinicians, families and the legal profession must make decisions not over whether very ill human entities can be kept alive, but whether they should be. Current controversies over such decisions at the beginning of life concern the stage of a pregnancy wherein termination should be lawful, the cut off point at which a baby who has been born prematurely with a poor prognosis should not necessarily be resuscitated and when it can be seen as in the best interests of a severely damaged baby to be allowed to die. The impact of new medical technologies, particularly imaging techniques which provide information on internal states of being in unprecedented depth, on public involvement in policy making has been significant. Images of foetuses in the womb sucking thumbs, reportedly able to feel pain and to recognise the voices of family members, have influenced public perceptions of the beginning of life as well as official policies. Medical imaging has become domesticated as a result, as expectant parents routinely make copies of ultrasound images of their future offspring, and know whether to anticipate a boy or a girl. Thus, while imaging technologies provide evidence to underpin guidelines and policies on controversial beginning of life issues, they also raise specific ethical dilemmas over the broad personal and social meanings attributed to neuroimages (Racine et al. 2006). Yet the clinical evidence neuroscience provides may be drawn upon to construct nuanced ethical foundations for policy deliberations. This potential has been demonstrated in the Nuffield Council on Bioethics' highly impressive recent report on critical care decisions in foetal and neonatal medicine, where the emphasis on evidence bases rests in part on a measured appreciation of the potential of medical technology to support ethical decision making (Nuffield Council of Bioethics 2006). In my view, neuroscientific techniques afford a similar potential for

*Published version available in 'Freeman, M, (eds). Law and the Brain. Ashgate Publishing, London, UK'*

providing information to underpin ethical decision making at end of life, and to expand the range of choices available here. The remainder of this section will sketch out this claim.

Neuroimaging techniques permit brain activities and mechanisms to be matched with subjective experiences and behaviour patterns. While first person accounts of subjective experiences cannot be authenticated using objective, third person measurements, multimodal functional brain imaging techniques (EEG, ERP, MEG, fMRI and PET), now may map brain mechanisms and alterations in such a way as to correlate these with cognition and consciousness (Harneroff 2005). Degrees of activity in specific areas of the brain are associated with experiences of particular feelings like happiness, spiritual enlightenment, or fear (Haidt 2006). Engaging in specific behaviours may trigger such activity deliberately: Tibetan monks mediating on universal compassion demonstrated an ability to manifest gamma wave synchrony associated with a higher form of consciousness, as measured by EEG (Harneroff 2005; Lutz et al 2004). In addition, stimulation of specific areas of the brain provokes characteristic responses. For instance, the feeling of a sensed presence, or Sentient Being, associated in many cultures and times with subjective experiences of spirituality and mysticism, may be provoked by stimulation of the right hemisphere with weak complex magnetic fields, and measured in terms of alpha waves and temporal lobe activity (Booth et al 2005). Neuroimaging technologies also have the capacity to map subjective experiences as they manifest in neurotransmitter activity. Human behaviour and moods are largely mediated by dopaminergic and serotonergic systems, where rewards, motivations and arousal are associated with regulatory neurotransmitter mechanisms (Saah 2005). These vary with circumstance and medical condition. Those addicted to alcohol, or suffering from certain mental disorders are likely to evidence characteristic disruptions in serotonin and dopamine processing in the brain (Kapur and Lecrubier 2003). Thus the therapeutic potential of neuroscientific means of assessing neurotransmitter mechanisms in order to restore health and homeostasis holds much promise as a basis for future clinical treatments based on detailed knowledge of such brain structures and mechanisms.

These techniques of measurement and stimulation also afford the possibility of investigating the neuroscience associated with end of life, including the experience of the dying process. My suggestion here is that in the same way as beginning of life policies are informed by the impact of imaging techniques, equivalent evidence over end of life mechanisms should be accumulated as underpinning for salient ethical, legal and medical decision making. Given that developmental factors influence not only the beginning, but also the ending of our lives, it makes sense to investigate both. By and large, our knowledge of the neuroscience of what happens as we embark on the dying process is partial at best. Rather than focus on the dying process itself, neuroscientists have tended to investigate specific clinical conditions associated with ethically problematic states of being. Nonetheless, researchers have recently begun to draw upon neuroscientific technology in an attempt to provide detailed, integrated explorations of the neural, behavioral, and computational correlates of altered states of consciousness such as brain death, coma, vegetative states, minimally conscious state, locked-in syndrome, dementia, epilepsy, schizophrenia, hysteria, general anesthesia, sleep, hypnosis, and hallucinations as a basis for ethical decision making in these areas

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(Laureys et al. 2006). I would argue that such investigations should be extended to how we die and the neuroscience of the dying process, not only to ensure better medical care, but also to provide us with enhanced choices which include enhancing the dying process in order to achieve what we would regard as a good death.

## **Neuroscience, psychedelics and reframing the good death**

What, then, is a good death? I would suggest that there are ways in which we could dispel some of the uncertainties which prevent our answering this question with more specificity. While what happens after death remains, and seems likely to remain, contentious, research into the neuroscience of the dying brain offers us the potential to enhance choice in death by enhancing dying. So far, this constitutes unknown territory. How, then, might our dying process be enhanced?

Neuroscience has much to offer here in that it also possesses the potential to extend our knowledge of how end of life states of being relate to psychoactive substances. In that these may be both produced internally, or endogenous, as opposed to taken in from external sources, or exogenous, their role in health is of central importance. Indeed, medical treatments at end of life commonly rely upon exogenous psychoactive substances in the form of opiates and their derivatives to control pain, as well as psychiatric medications to ameliorate dementia, depression, anxiety and agitation. Research involving exogenous psychoactive substances which are also used as unlawful recreational drugs has been seen as permissible only recently (Check 2004; Mackenzie 2006; Nichols 2006). Recent clinical trials seek to assess the potential of otherwise unlawful psychoactive substances to ameliorate depression and anxiety in the terminally ill (Morris 2006), cluster headaches (Sewell et al. 2006), post traumatic stress disorder and other forms of psychotherapy including treating addictions (Sessa 2006). Psychoactive substances such as LSD, psilocybin, mescaline, ibogaine, ayahuasca, MDMA or ecstasy and salvia divinorum have all been found to have clinical potential as a result. For the purposes of this paper, and for reasons of space, only the possibility of enhancing subjective experience of end of life processes with psychedelics will be considered further.

Psychedelic, or mind manifesting, psychoactive substances are also known as hallucinogens (producing hallucinations), psychotomimetics (mimicking psychosis) and entheogens (revealing the God within) (Kleber 2006). Neuroscientists have recently conducted rigorously constructed double blind active and inactive placebo controlled studies characterising subjective, physiological and perceptual effects of various psychedelics, with follow ups to evaluate long term effects (Griffiths 2006; Nichols 2006). These have revealed not only the role of neurotransmitter mechanisms in their effects (psychedelics are serotonergically mediated, but may resemble norepinephrine and dopamine as well as serotonin) but also demonstrate the promise of neuroimaging for explaining the sites and mechanisms of action of hallucinogens and the workings of consciousness (Snyder 2006). The effects of psychedelics on the neurobiology of body perception and awareness (interoception) and emotional processing has also been demonstrated using

SPECT and PET imaging techniques (Riba et al. 2006). Such studies have consistently demonstrated that psychedelics promote spiritual or mystical experiences which tend to have long lasting positive effects on the subjective experience of life. These resemble spontaneously occurring mystical states associated with the dissolution of ego boundaries and feelings of transcendence, or merging with the universe, and it is postulated that both are mediated by changes in serotonin mechanisms (Haidt 2005; Snyder 2006). Their therapeutic potential is seen as highly promising for treatment of intolerable pain, refractory depression and the sufferings of the terminally ill, as well as for humanistic psychology, substance abuse and dependence (Friedman 2006; Kleber 2006; Kolp 2006).

Naturally there are caveats. Considerations of dosage, efficacy of different psychedelics, individual differences in response as mediated by genetics or context, and other issues associated with clinical judgements over risks and benefits would need to be addressed. Research into possible negative subjective experiences resulting from ingesting psychedelics would be essential before providing them as treatment or enhancement might be seen as lawful. Nonetheless, the promising nature of the results so far has led to calls for continuing research on the basis of probable therapeutic benefit, as well as increased insights into the nature of consciousness and cognition (Girffiths et al 2006; Kleber 2006; Nichols 2006; Saah 2005; Schuster 2006; Sessa 2006; Snyder 2006). The positive effects of spiritual experiences promoted by psychedelics in enhancing subjective feelings that life has meaning possess obvious potential for palliative care, including the possibility of reducing or replacing medication for pain, anxiety and depression, as well as the associated unwelcome side effects.

Spiritual convictions that one's life is meaningful have the highest correlation with subjective assessments of quality of life amongst cancer patients and their spouses (Axelsson and Sjoden 1998). The current orientation within palliative care is to improve quality of life and to relieve suffering (Kim et al. 2005). Positive psycho-spiritual well being is seen as central to patients' ability to find meaning in the experience of terminal illness by clinicians involved in palliative care throughout the world (Lin and Bauer-Wu 2003). Palliative care ethicists distinguish between the intrinsic aim of palliative care, to bring about a medical good; and the extrinsic aim, to promote the patient's psychological, emotional, relational and spiritual good. Randall and Downie argue that phronesis, or the practical wisdom to deal with a range of issues relating to the extrinsic aims, is the controlling moral component in all palliative care. Phronesis is essential if clinicians are to appreciate the meaning of the disease, suffering and treatment for each particular patient, and to respect how that meaning fits into the patient's conception of their total good (Randall and Downie 1999, 1-28). From this perspective, the possibility of including the administration of clinically approved psychedelics on request in palliative care provision as coming within the ethical aegis of beneficence or phronesis seems initially plausible. Yet allowing us to request psychedelics to enhance a spiritual sense of meaning at end of life may not be simply accepted as clinical treatment. Should providing this choice be framed as enhancement, many are likely to find

such an option objectionable. The following section will consider the reasons why this might be so.

### **Reframing the good death to enable enhanced choice and enhanced dying**

I wish to argue in this section that the discourses surrounding choice in dying and notions of the good death are currently impoverished. My suggestion is that the good death be reframed to include enhanced choice in death by providing us with options over how our dying might be enhanced. Such a prospect may seem odd. I shall argue that this is so because of an historical relationship between the discursive strategies adopted within the separate debates surrounding assisted dying, enhancement, the regulation of psychoactive substance use and how these should relate to medical treatment. In my view, concerns over risks associated with hereditary enhanced genetic characteristics and the controversies surrounding medically assisted death, taken together with troubled cultural relationships with pleasure, have resulted in a degree of rhetorical capture. As a consequence, any association between medical treatment, enhancement, pleasure and death has been rendered, to a degree, unthinkable. Enhancement has been discursively constructed as applicable largely to inherited characteristics, pleasure through psychoactive substances read as addiction and medically assisted dying equated with hastening death in response to patients exercising a tightly constrained autonomy. I have no desire to retrace the arguments in each of these debates. Instead, I wish to draw from them in order to propose a reframing of the good death as one wherein we could choose to receive medical assistance to enhance our dying.

How far, and in what way, if at all, we should place ethical and legal limits on enhancement technologies is not self-evident. Ethicists, politicians, the bioscience industry and the public seem unlikely to arrive at a negotiated consensus here (Fukuyama 2002; President's Council on Bioethics 2003; Smith 2005). Opponents of enhancement tend to proscribe it as interfering with nature, or to argue that medical treatment is ethically permissible, but enhancement is unethical (Sandel 2004). Psychoactive substances constitute a special category where the enhancement of human capacities and moods is concerned (Foresight 2005). While pharmaceuticals like Prozac, Modafinil and their progeny demonstrate the commercial potential of such products, ethical and legal limits have been placed on their availability. Nonetheless, many such drugs, ostensibly used to ameliorate difficulties associated with medical conditions, have crossed over into the off-label mainstream where they are used to enhance performance or mood. Pharmaceutical manufacturers holding a multitude of patents nearing the ends of their useful lives, need to find new markets and new products in order to sustain profitability. Yet the relationship between psychoactive substances which lead us to feel better as well, and better than well, is a troubled one. Many, like the opiates, are controlled substances whose use is prohibited unless prescribed. Nonetheless, much non-prescription use of these takes place outside the law, either through diversion of prescribed medications or illegal manufacture. The lack of congruence between the legality of psychoactive substances and their favourable or harmful effects on our health is problematic for the public health and criminal justice



authorities which seek to persuade us to maintain our health and to respect the law (Mackenzie 2006; WHO 2004). For pharmaceutical companies, though, the salient problem is that patent protection extends only as far as new effects of old substances, or to new substances. Where the latter function to enhance the moods or capacities of the healthy they are liable to be designated as unlawful designer drugs. This leaves the industry in a situation of moral hazard, where yielding to the temptation to create new disease entities cured by new 'lifestyle' drugs has been condemned as 'disease-mongering' and strategic deployment of the rhetoric of choice and need (Biggs and Mackenzie 2000; PLOS Medicine 2006).

All this has deleterious effects where research into enhancing dying through pharmaceutical means is concerned. Since most psychoactive substances which might do so are not new or, frequently, lawful, their ability to attract patent protection would be uncertain, so that the financial incentive for pharmaceutical companies to place research and development funds into this area is minimal. As palliative care organisations are usually charities, their resources from which to fund research are limited, as well as their orientation being to soothe rather than enhance the dying process. In addition, as outlined above, research into dying is acknowledged to raise special issues (Field et al. 2001; Jubb 2002). Yet these practical difficulties are outweighed by ethical and legal factors. It is upon these I wish to focus for the remainder of this article.

My starting point is the assertion that current debate over end of life decision making has been curtailed by a degree of rhetorical capture. Self-evident concerns over the integrity of the medical profession, the appropriate limits on autonomy and the protection of the vulnerable have ensured that considerations of patient choice in relation to our dying have been restricted to whether and in what circumstances medically assisted dying might receive ethical and legal approval. As a consequence, the means by which clinicians might provide treatment which would enhance our subjective experience of the dying process has received scant consideration. In particular, the opportunity for a role for patient choice in medically enhanced dying has not, as far as I am aware, been mooted previously. In my view, a salient additional factor is that ethical discourse over enhancement has been overdetermined by that already put in place by controversies over the new reproductive technologies. Together with this, research into the neurochemistry of the promise for enhancement afforded by psychoactive substances has been compromised by injudicious past practices (Mackenzie 2006; Nicols 2006). My suggestion is that severing criteria for permitting enhancement from an association with inheritable characteristics should permit a focus on how the dying process might be enhanced in ways which might prove beneficial to many. This would be anchored by an evidence base obtained via research into the neuroscience of the dying process, as providing the potential for an investigation of the subjective effects of psychoactive substances in this context, as outlined above.

Should this be framed as optional clinical treatment rather than consumer demand, there is the potential for enhancement of the dying process, based upon highly structured ethical studies, to be viewed as falling within healthcare professionals' obligation to treat their patients with beneficence, as an extension of current palliative care measures. Future possibilities, and how these might relate to legal issues and patient choice, will be explored in this light.

## Decision making, death and dying and the law

Most of us would like some choice over how, where and when we die. While such decisions are inherently restricted by the vagaries of incarnation and the mishaps of fate, we are able to exercise a degree of choice over dying where healthcare is concerned. We may refuse medical treatment altogether or eschew specific measures, although we cannot request and receive those which are seen as clinically unjustified (*R (On the Application of Burke) v General Medical Council (Official Solicitor and Others Intervening)* 2005 3 WLR 1132 and the European Court of Human Rights decision to refuse Mr Burke the chance to appeal against this judgement

<http://cmiskp.echr.coe.int/tkp197/view.asp?item=2&portal=hbkm&action=html&highlight=burke&sessionid=8546023&skin=hudoc-en> ). Nor can we, in the United Kingdom, ask for, and receive, assistance to die. Should some future version of the Lord Joffe's Assisted Dying for the Terminally Ill Bill become law, those of us who are terminally ill, suffering unbearably and competent may be lawfully provided with the means by which we might end our own lives by healthcare professionals provided certain safeguards are in place (Parliament 2006). Although assisted suicide, voluntary and involuntary euthanasia are available within the law in certain countries in Europe, common law jurisdictions almost universally prohibit assisted suicide and all forms of active euthanasia (Marker 2006). This stance is associated with a reading of death as appropriately falling within the aegis of medicine; logically enough in that most of us die subject to clinical judgements, either that treatment has failed to save us or that further treatment would be futile. From this perspective, a good death involves the caring healthcare professional's relieving suffering, providing palliative care and hastening death, without the intention to do so, only where there has been a refusal of treatment or where pain relief does so as a side effect. Thus, medical assistance in our dying is subsumed under beneficence, the duty to relieve patients' suffering. The correlative duty to respect patients' autonomy applies insofar as patients may refuse treatment, but clinical judgement prevails over autonomous requests for either hastened death or specific treatments which are regarded as clinically unjustifiable.

Many believe that a good death should be interpreted otherwise. Requesting assistance to die has been framed in terms of autonomy, dignity and relief of intolerable suffering (Biggs 2001). All of these terms have contested meanings (Pullman 2002; Singer 1996). Widespread agreement on what they signify, or how they should relate to clinical judgement and patient or human rights is highly unlikely (Williams 2005). I have no wish to traverse these well-rehearsed positions yet again. Instead, I wish to propose a widening of the debate to reframe the good death as incorporating the possibility of enhancing the dying process.

In my view, our choices over dying need not be restricted to whether or not it should be seen as ethically acceptable and lawful for patients to request medical assistance in dying only in the sense of actively hastening death. This is essentially a negative choice to avoid specific consequences like ennui, dependency or feeling like a burden. Reading ennui, dependency or feeling like a burden as suffering might lead to a view of medically assisted death as ethically acceptable, through a combination of respecting patient autonomy, in terms of allowing a

choice to die, and providing beneficence, in terms of relieving suffering. Yet concerns over the integrity of the medical profession, preserving trust as an element of the clinician/patient relationship and affording protection for the vulnerable have so far prevented active medical assistance in dying from becoming lawful in most jurisdictions. Even in those where it has become lawful, the good death has not been reframed to enhance choice through providing means to enhance dying. I shall now explore reasons why this has not taken place, in order to argue that a degree of rhetorical capture has prevented this.

### **Reproductive technologies, enhancement and death: rhetorical capture**

It is now a truism to say that death has replaced sex as spectacle as the transgressive impact of the latter declines (Carnell 2000). The resurgence of public autopsies, exhibitions of corpses and an unrelenting media focus on mortality induced by others denotes a [re]current cultural fascination, following on from the demystification of sex and reproduction which preceded it (Kuppers 2004; Tait 2006; van Dijck 2001). I wish to suggest here that the deconstruction of death and dying parallels that of sex and reproduction, specifically in that the ethical and legal controversies over choice and autonomy exhibit the same rhetorical concerns. Debates tend to centre about an opposition constructed between a quest for secular ethics and a positioning of technology as the enemy of the sacred. Of note here is that technology as enabling the deconstruction of 'life itself' fosters specific rhetorical tropes wherein life, nature and the sacred are regarded as threatened by autonomy and choice (Mackenzie 2007). This has been explicated in relation to debate over the regulation of the new reproductive technologies, the Warnock report and the Human Fertilisation and Embryology Act 1990. Feminists have demonstrated how resolution was achieved via strategies involving the creation of a new entity, the pre-embryo, the medicalisation of infertility and the sacralisation of motherhood, which together rendered acceptable the new reproductive technologies (Franklin 1993; Mulkey 1997; Spallone 1996).

One argument I am making here is the assertion that much of the current debate over death and dying has been subjected to rhetorical capture. The discursive rhetoric surrounding reproductive technologies has been transferred to ethical considerations of death and dying. This rhetorical capture of how we die has foreclosed and constrained the symbolic universe within which we currently conceive of the dying process. By and large, the new reproductive technologies have faded into the background of our ethical landscape. Cultural dissension where sex and reproduction is concerned tends to be sited in the rearguard actions mounted by those who oppose abortion as part of family planning and support marriage as a solely heterosexual institution. Much of the shock of the new has transferred to finding a common language for ethical discourse over 'death itself' as opposed to 'life itself'. Thus the extension of the dying process made possible by technology, in-between states like persistently vegetative states and the varying medical and legal ways in which death itself may be defined have together produced a discursive environment very similar to that which surrounded the new reproductive technologies around thirty years ago.

Enhancement is one arena where controversy over reproduction remains. Condemned along with cloning and stem cell technologies as unnatural, against

human dignity and a crime against humanity by influential bioethicists, enhancement as deliberate alteration of inheritable human genetic characteristics is also proscribed in significant international agreements (Annas 2002; Fukuyama 2002; Kass 2002; President's Council on Bioethics 2003). Transhumanists and others who favour such enhancement, or who see it as inevitable given its technological temptations and commercial potential, regard such bioconservatism as philosophically suspect in that it is based upon overly narrow conceptions of humanity, dignity and autonomy (Bostrom 2005; Smith 2005; Stock 2002). In addition, all concerned disagree upon how best to assess and evaluate the risks of altering the human germline.

My point here is that the rhetoric of the cultural debate over 'life itself' is misleading for ethical and legal decision-making over 'death itself'. For a start, medically enhanced dying would not involve unforeseeable hereditary change in the human germline. In addition, where 'life itself' is concerned, the disparate groups whom Brownsword has designated as the 'dignitarian alliance' rely upon the concept of dignity to constrain rather than extend choice (Brownsword 2004). 'Designer babies', reproductive cloning and manipulation of the human germline are all seen as offending against human dignity and the proper relationship between humans, nature and life itself (Lauritzen 2005; Sandel 2004). While some philosophical inquiries into dignity have concluded that predetermination of human genetic characteristics and some manipulations of the genetic heritage of humans need not be seen as offending against human dignity, despite statements of principle in various international instruments, this is not a common viewpoint (Bostrom 2005; Smith 2005). Brownsword characterises the stance of the dignitarian alliance as in opposition to a pragmatic reduction of the salient ethical issues to the secularised touchstone of a risk/benefit analysis based upon the precautionary principle. From the latter perspective, choice over enhancement in reproduction would be subject to restrictions based upon interpretations of the idea of dignity as well as those posed by unforeseeable inherited consequences. Yet it is not self-evident that this need be so where dying is concerned.

Enhancement, dignity and choice can all be seen to have context-specific meanings. Should the rhetoric of new reproductive technologies be simply transferred to decisions governing 'death itself', it would therefore constrain them in an inappropriate fashion. I would argue that this transfer has taken place, with consequent limits being placed upon how we conceive of the ethics of possibilities associated with our dying. Notions of dignity are currently deployed to shape choices over how we reproduce in a way which excludes enhancement. This is commonly achieved through linking the idea of dignity to a naturalised sacralisation of the current human genome which defines humans with enhanced genetic characteristics as lacking in human dignity (Smith 2005). The human genome becomes linked to nature as sacred human tissue properly immune to technical manipulation (Lauritzen 2005; Sandel 2004). Even where the ethics of enhancement aside from rerogenetics is in question, an ostensibly secular debate is imbued with terms and symbology associated with religion and the sacralisation of nature by those who oppose it (Strong 2005).

I would argue that this conflation of the natural, the sacred and the viewing of technical intervention as offending against dignity, as developed in the discourses

of reproductive technologies and enhancement, impoverishes the current debate over how far and in which ways we should be able to exercise choice in dying. The terms, perspectives and ways of thinking associated with dissension over reproductive technologies and the limits which should be placed on enhancement with respect to reproduction have created a rhetorical symbolic universe which has been applied to debates over end of life issues in ways which create confusion. An example of this may be seen in the ongoing dissension over whether artificial nutrition and hydration constitute medical treatment, which may be withdrawn on request or according to clinical judgement, or basic care, which should continue. Guidelines over hospice and palliative care typically characterise dying as a natural process wherein artificial nutrition and hydration form part of basic care until the dying process begins, whereupon artificial nutrition and hydration become categorised as intrusive technological intervention (Frederick 2002). The dying process, from this perspective, thus becomes sanctified, naturalised and ideally subject to minimal medical intervention. Thus the concept of dignity, when applied to death and the dying process in the context of withdrawal of treatment, sanctifies the natural and opposes it to intervention. Both legal and medical professionals speak of providing dignity in death in terms of 'letting nature take its course' as part of respecting the sanctity of life (Keown 2005). Dignity here is equated with not taking heroic measures to preserve life when to do so would be futile, but allowing the naturalised dying process to proceed. The extent to which this use of both dignity and nature represents rhetorical strategy may be seen when we consider that medical intervention inherently interferes with the natural processes associated with ill health, and that is indeed why we seek it when we are unwell. Certainly once we begin to die we lose our appetites and our fluid intake diminishes. Yet how far away the rhetoric of 'letting nature take its course' might be from most understandings of dignity is revealed by the fact that the result of the decision to do so often results in conceptually distinct situation of patients, who were not otherwise dying, slowly doing so from starvation and dehydration once artificial nutrition and hydration has been withdrawn (Brogden 2001). Thus drawing upon cultural conceptions of dignity which sacralise and naturalise the process of dying with minimal medical intervention circumscribes debate over when and by what means we should die when we are not expected to recover.

Brownsword's model of a policy opposition between the dignitarian alliance and autonomy driven risk/benefit libertarianism as traversed above fits the discursive dissension over reproductive technologies better than that over death and dying. Here both those who oppose and those who support medically assisted dying lay claim to the term dignity, the former as outlined above and the latter as exemplified in the recent decision by the Voluntary Euthanasia Society to change its name to Dignity in Dying. Strong conceptions of autonomy in this context sever notions of dignity from the natural where death is concerned. Thus, when those who conceive of a good death as potentially incorporating active medical assistance in dying wish to be able to request death, or claim a right to die, once they feel that to continue living would involve an intolerable lack of dignity, they do so on the grounds that dignity is compatible with autonomy but not dependence. Such a death, then, is denaturalised not only in terms of incorporating medical care, but also in relying upon it to curtail the dying process. The merits of medically assisted death and its relation to dignity have been debated elsewhere often, and I do not propose to revisit them. Nonetheless, this position suggests that while dignity might act as a

fetter upon choice where reproduction is concerned, once the concept of dignity is separated from that of nature in relation to how we die, its use within debates over medically assisted dying is both strategic and incoherent. Thus, in my view, there is no reason why conceptions of dignity should restrict how we exercise choice here. Indeed, despite its presence in many international agreements, human rights jurisprudence and cases concerning death such as *Pretty v United Kingdom* (Application 2346/02) [2001] 2 FCR 97, the value of the concept of dignity as an ethical tool may be seen as limited without specific definition (Hayry 2004; Hayry and Takala 2005).

I have suggested above that choice over medically enhanced dying need not be circumscribed by conceptions of dignity, since in the context of death and dying these are so various as to lack persuasive force, and that ethical objections against enhancement which are mounted within reprobogenetics debates do not apply here. Nonetheless, were these suggestions to be found acceptable, the way forward to enhancing the dying process is not clear, as cultural attitudes towards pleasure and suffering come into play. I shall consider these first in relation to sex and reproduction before assessing their impact on my arguments.

The nexus between sex, reproduction, pleasure and suffering possesses contested cultural significance. Sex, birth, death and dying are all processes which are part of life for most of us. The degree to which they should be medicalised, given that they are not, strictly speaking, illnesses, and the amount of choice we should be able to exercise over them remains contentious. These questions have been mapped onto other debates over the appropriate reach of medical services, consumerism and enhancement. As a consequence, arriving at consensus over how they should be associated with already culturally overlaid experiences such as suffering and pleasure is not a straightforward process. An example here is the biblical association between childbirth and suffering as punishment for Eve's yielding to the snake's temptation: 'in sorrow shalt thou bring forth children' (Genesis, 3:16). While it is now accepted that pain relief in childbirth is appropriate medical care, how far requests for elective caesarians might be seen as acceptable remains unsettled. That sex and reproduction are no longer necessarily causally connected has facilitated the commodification and celebration of sexual pleasure which characterises our times. Yet their deconstruction has also been accompanied by an encroachment of medicalisation, as in the creation of the disorder female sexual dysfunction, a condition allegedly suffered by almost half of the women in the United States (Laumann et al. 1999). Thus the enhancement of bodily processes which are not in themselves illnesses ends up being characterised in these terms, with the medical profession as gatekeepers or overseers, in circumstances requiring compromises between medical ethics and consumer choice.

This impacts on enhancing dying as follows. While the deconstruction of sex and reproduction has permitted an open personal and commercial focus upon sexual pleasure and its enhancement, cultural differences mean that this has proven a troubled pathway. Historic associations between sexual pleasure, perceptions of immorality and tawdry commerce tainted and delayed research until the mid-twentieth century. Similar associations hamper the accumulation of an evidence base on enhancing dying. The combination of pleasure and death calls forth memories of serial killers, snuff movies and similar forms of popular entertainment

which it is easy to decry. Psychoactive substances and dying are linked not only to the relief of suffering in medical treatment but also with entertainers and addicts taking lethal overdoses and imprudent practices involving hallucinogens within academia in the 1960s and 1970s. Yet the deconstruction of dying and death affords opportunities for enhancement which parallel those associated with sexual pleasure today. If we are to be granted more autonomy over the dying process when recovery is no longer possible, should we also not have some say into the means by which we do so?

A logical response here is that while pleasure is the biologically driven response to sexual activity, the same cannot be said for our dying. It is here that I wish to turn to the neuroscience of daily life, in order to argue that our biological substrates and many reports of dying experiences suggest that the situation may be more complex. In everyday life, to be happy is to be healthy, other things being equal. Research into the neuroscience of health reveals that enhanced health is associated with an overall sense of coherence, or a global orientation to view the world and the individual environment as comprehensible, manageable and meaningful. Instruments for measuring how such beliefs and practices are associated with good health have proven cross-cultural validity and reliability (Eriksson and Lindstrom 2005). In addition, pleasure not only enhances our health but forms a basis of action and interaction in our daily lives. For example, recent research suggests that the release of endogenous opiates ensures that we enjoy one another's company, providing evidence for a postulated human trait of affiliation (Depue and Morrone-Strupinsky 2005).

Associations between certain states of being or beliefs and practices and good health are now accepted, while investigations into the neurocircuits in the brain associated with functional mechanisms that contribute to health via specific beliefs and practices are ongoing. For instance, maintaining good health despite stressful situations is associated with the belief that things will work out as well as can reasonably be expected, being mutually in love, believing in God and expecting things to change for the better (Smith 2002). Such beliefs need not be rational or realistic for them to function in this way, as evidenced by the placebo effect, which involves the brain's reward pathways and stimulates feelings of well being (Esch and Stefano 2004). Neuroscientists recommend being in lust or in love as the associated pleasures reduce anxiety and stress, enhance health and promote sociality (Esch and Stefano 2005a). In fact, all varieties of love accompanied by pleasure appear to offer health benefits (Esch and Stefano 2005b). This first came to the attention of neuroscientists through research projects associated with the love of the divine (Lee and Newberg 2005). Investigations into spiritual practices, medicine and neurotheology previously associated such health promoting effects specifically with religion and religious activities such as prayer (Sloan et al 2000). More recently, however, subsequent research suggests that any shared strong belief system accompanied by regular rituals will produce identical health benefits (McGuire and Tiger, 2006). Thus a congregation of atheists who meet regularly to affirm their beliefs in ritualistic fashion could be expected to experience similar feelings of well being as would those of an equivalent group of those with religious faith. What these findings tell us is that good feelings promote good health. If we feel that life makes sense, that we can deal with its difficulties, and are able to love at least some of our lives, our gods and our fellow men and women, then we are

more likely to be healthy than if we do not, and to recover better from ill-health (Mackenzie 2006).

This neurochemical model of how we live suggests that feelings of bodily produced pleasure underpin happiness, sociality and health (Depue and Morrone-Strupinsky 2005; Katz, 2005; Smith 2002). In addition, experiences of subjective meaning, whether these are produced by love, belief or social rituals, enhance how we experience our lives as well as promoting health. Indeed, many mental and mood disorders, as well as many of the effects of the aging process, may be explained in terms of neurotransmitter dysfunction within the brain which interfere with the ability to experience life as pleasurable (Charney and Nestler 2004; Keverne and Ray 2005; Reynolds 2005). Psychoactive substances may enhance or substitute for these mechanisms, as their effects on the brain frequently mimic the neurochemical mechanisms involved. For instance, opiates administered as part of medical treatment to ameliorate pain do so as correlative endogenous opioids also effect analgesia (Li et al 2004). The endogenous cannabinoid system is involved in the reward circuitry which provides the experience of pleasure, as well as affecting appetite, pain and the immune system. Evidence that this malfunctions as a result of certain medical conditions like advanced cancer, diminishing the ability of patients to experience pleasure (Lissoni et al 2003), adds force to the argument I am making here that providing us with the choice to enhance our dying might be ethically compatible with both beneficence and palliative care.

If the substrate of daily life, health and well being is based upon the neurochemistry of pleasure and subjective experiences of meaningfulness, it becomes more difficult to argue that the clinical administration of substances which produced such effects at end of life should be seen as unnatural. While some may argue that producing spiritual experiences through psychoactive substances denigrates from their validity compared to those which arise of themselves, those who tell of the former, whether these take place in sacramental or experimental contexts, tend to express no such doubts (Griffiths 2006; Riba 2006). Nonetheless, where the intention is to provide an option of enhancing the subjective experience of dying, this could be proscribed as enhancement rather than treatment. Several ethical issues are salient here. Those who argue that an ethical distinction between treatment and enhancement is sustainable (Sandel 2004; Schwartz 2005) are opposed by those who find this position incoherent (Kamm 2005). Others argue that the context and meaning of enhancement should govern its ethical acceptability (Martin and Peerzada 2005; Robert 2005). In addition, the relationship between enhancement and professional integrity is a troubled one. Those who have concerns over what they see as inappropriate patient choice over enhancement, where the doctor/patient relationship becomes one of consumer and service provider, seek to prevent a future where medical ethics reduces to the ethics of marketplace transactions (Miller and Brody 2005).

Given the flexibility of disease taxonomies when commercial opportunity beckons, as sketched out above, it seems likely that research into the neuroscience of end of life would reveal processes and mechanisms which might be framed as in need of clinical treatment. In the same way as the manifestations of aging, such as pigmentation anomalies, may be categorised as forms of ill health, aspects of end of life could lead it to be seen as a disorder of some kind. Options to enhance end



of life care could then include the provision of clinically approved psychedelics to promote feelings of meaningfulness associated with quality of life, as well as ameliorating symptoms of anxiety, depression and ennui. Taxonomies at end of life could prove central to the legalities of research on human subjects at end of life. It is to these complexities that I will now turn.

### **Legal and ethical considerations in research on end of life human subjects and enhancing the dying process**

Research on human subjects at the end of their lives as outlined above would involve neuroimaging to measure both the neuroscience of the dying process and the impact on the subjective experience at end of life of administering psychedelics and active or inactive placebos. The ethical and legal requirements for gaining research ethics committee approval for such research, involving firstly the neuroscience of the dying process and secondly the neuroscience of the impact of the administration of psychedelics at end of life will now be considered. The salient features of the research governance structures will be outlined, then applied to each case.

Research on human subjects in the United Kingdom is governed by a combination of legislation, regulation and guidelines. While all research trials on human subjects should be approved by an ethics committee, clinical trials of pharmaceuticals and research on those without mental capacity are subject to specific regulation. Good clinical practice over research into medicines for human use is governed by the Medicines for Human Use (Clinical Trials) Regulations 2004, which incorporate European Directive 2001/20/EC into domestic law. Regulation 28, which provides that clinical trials must be carried out 'in accordance with the conditions and principles of good clinical practice', gives lawful force to criteria contained in international codes of research ethics, such as the Declaration of Helsinki. In addition, Schedule I, Part II, specifies that trials should take place only where anticipated benefits for the trial subject and other present and future patients outweigh foreseeable risks (s. 2); that the rights, safety and well being of the trial subjects should prevail over the interests of science and society (s. 3); and that freely given informed consent should be obtained from competent trial subjects (s. 9). Schedule I, Part 3, elaborates on the requirement for informed consent for research subjects who are either able to consent, or who have given their consent prior to the onset of incapacity.

Mentally incapacitated adults who are incapable of giving consent are not necessarily precluded from becoming research subjects. Provided that it is impossible to carry out the research on those capable of giving consent; that the research is likely to benefit either the individual concerned or members of the group to which they belong; that efforts to gain assent have been made; that evidence of a desire not to participate in the research should be decisive; and that the risks involved in non-therapeutic research are no more than minimal unless there are exceptional circumstances; such research may be conducted lawfully provided consent has been obtained from the incompetent person's legal

representative. This consent should be based upon both information about the trial, the presumed will of the proposed research subject and a continuing evaluation of how far participation in the research remains appropriate.

Under Schedule I, Part 4, additional conditions and principles which apply to incapacitated adults specify that the proposed research subject must have received information about the risks and benefits of the trial tailored to their ability to understand it; that where any capacity to understand this information is present, any explicit wish to refuse to participate or be withdrawn from a trial must be considered by the investigator; that no incentives or financial rewards be provided to them or their legal representative; that there are grounds for expecting that the medical product to be administered would produce a benefit to the subject outweighing the risk or produce no risk; and that the trial relates directly to a life threatening or debilitating clinical condition suffered by the proposed research subject.

These concerns are mirrored in professional guidelines. For instance, s. 48 of the guidelines on research produced in 2002 by the General Medical Council specify that research on incapacitated adults should not be carried out where it could equally well be carried out on other adults (General Medical Council 2002). It should be limited to their incapacity or physical illnesses linked to this. Such research may be carried out only where it has been demonstrated that: it could be of direct benefit to the health of the research subject or to that of people of the same age group with the same state of health; that it would significantly improve the scientific understanding of their incapacity leading to a direct benefit to them or to others with the same incapacity; and that the research is ethical and will not cause emotional, physical or psychological harm to participants; and there is no physical or verbal expression of objections. Any sign of distress, pain or indication of refusal is to be considered as an implied refusal. Guidance issued by COREC, the Central Office for Research Ethics Committees, elaborates on finer points outside the Clinical Trials Regulations. For instance, should a capable adult give informed consent to take part in a clinical trial, then subsequently lose capacity, the consent will remain legally valid (COREC 2006).

Additional statutory provisions for research carried out on incapacitated adults may be found in the Mental Capacity Act 2005, which comes into force in October 2007. Many of the safeguards and principle in the Clinical Trials Regulations are mirrored in the portions of the act dealing with research. A key principle of the Mental Capacity Act is that individuals are presumed to have capacity unless otherwise demonstrated. Once incapacity has been established, the consent of a third party, based upon the past and present wishes of the incapacitated individual must be obtained before research may proceed. Under s. 30 of this act, 'intrusive' research carried out on, or in relation to, a person who lacks capacity to consent to it is unlawful unless certain conditions are fulfilled. Research defined as 'intrusive' under s. 30(2) of the Mental Capacity Act 2005 is research of a kind which would be unlawful if it were carried out without consent on a person with the capacity to consent. Unless 'intrusive' research is subsumed under the Clinical Trials Regulations, it is unlawful under s. 30 unless it meets criteria in ss. 32 and 33. S. 31

provides that: the research could not be carried out on adults with capacity; that no more than minimal risk is involved; and that the proposed subject or others with the same condition will benefit. S. 32 lists criteria for consultation with carers or those with lasting power of attorney over the incompetent adult's participation in the proposed research and their powers and responsibilities, whereas s. 33 provides additional safeguards allowing for withdrawal where there are demonstrations of a wish not to participate, or where the research involves things which would be contrary to previously expressed wishes. Where research does not have the potential to benefit the subject, any additional risk or discomfort should be negligible or nil and should not significantly interfere with their freedom or privacy.

Not all of the ethical and legal criteria intended to form part of the Act's guidance are yet in place. Part 4 of the draft Mental Capacity Act Code of Practice, which formed the basis for a consultation exercise and which will appear in final form in late 2007, identified the processes that need to be followed in order to ensure research on incapacitated adults was lawful (Department of Constitutional Affairs 2006). These provisions were intended to apply to 'intrusive' research not covered by the Clinical Trials Regulations, which included participants who have an impairment of, or disturbance in, the functioning of the mind or brain that results in incapacity to consent to the research. The Department of Health also sought views on whether provisions in the Act which proposed arrangements for research involving people who gave their informed consent to participate then lost capacity found the appropriate balance between the need to allow long term research to continue while respecting the past and present wishes of the participants. In its response to the consultation exercise, the Department clarified that there was no requirement for researchers to constantly check the capacity of their participants, (Department of Health 2006)

How might this structure of research governance apply to the end of life research proposed in this piece? Where neuroimaging alone was involved, this would fall outside the Clinical Trials Regulations. In that neuroimaging would constitute 'intrusive' research under s. 30(2) of the Mental Capacity Act, should capacity be lost consent from a third party might have to be obtained for continued participation. There is some uncertainty here, which may be resolved in the final Code of Practice. Given that there is a presumption of capacity under the act, and that the Department of Health confirmed that researchers were not required to constantly check on the capacity of research participants, it seems probable that the initial consent provided by a competent person at end of life might suffice for much of the time. However, should capacity be clearly lost, there are several alternative possibilities. One is the use of advance research directives specifying a desire to participate in research after the onset of incapacity. While these do not feature in the regulatory scheme sketched out above, many scholars support their use, often as a supplement for third party consent as evidencing intention (Backlar 1998; Berghmans 1997; Bravo et al. 2003; Dukoff and Sunderland 1997; Gevers 2006; Rosenstein and Miller 2003). Where the onset of incapacity is anticipated during a research study, the consent procedure might include a statement of the participant's wishes should this occur. While these methods of providing advance consent are uncommon, given that third party's assessments of the wishes of

those whom they represent are often incorrect (Berghmans 1997; Bravo et al. 2003; Wendler 2000), building them into the research protocol seems sensible. Indeed, Alzheimer Europe favours campaigns to educate people to make advance directives which cover research participation (Gevers 2006).

However, these would not be the only hurdles. As end of life is likely to involve eventual incapacity, since no more than minimal risk is involved in neuroimaging (Rosen and Gur 2002), and that the research results have the potential to benefit others at end of life, the criteria of s. 30 might be fulfilled. One caveat here is that the others who may receive such benefits should suffer from the same condition. If end of life is accepted as a condition, as I have suggested above given the flexibility of medical taxonomies, this too might prove non-problematic. Provided the past and present wishes were clearly to participate in the research, it should also fall within ss. 32 and 33. As neuroimaging involves negligible risk or discomfort, and protocols are in place to ensure that the incompetent are made comfortable during procedures involving scanning, the research should not significantly interfere with freedom or privacy. Overall, then, it is likely to receive ethical approval.

Where neuroimaging accompanied the administration of psychedelics at end of life, the research would fall under the Clinical Trials Directive. Hence consent given while competent would ensure that participation remained lawful even should capacity be lost, provided assent to the procedures continued. Other ethical dimensions would centre about demonstrations of the safety of the psychedelics, favourable risk/benefit ratios and freely given consent. A central factor would be establishing the credentials of psychedelics as medicines, but given the accumulating evidence of their potentially beneficial effects as outlined above, this should prove possible. The increasing role of spiritual meaning within palliative care could then ground an ethical justification for the administration of psychedelics as an optional part of end of life care.

## **Conclusion**

This inquiry into how we might enhance choice in dying is a contribution to the current debate over how much choice we should have over how and when we die. My central argument is that enhancing choice over death should include medically enhanced dying, and that as neuroscience has the potential to allow us to reframe the 'good death' according to criteria drawn from an expanded evidence base, research into the neuroscience of the dying brain should become a priority. I began by considering pragmatic contextual reasons why this research has not taken place before arguing that there has been a degree of rhetorical capture of 'death itself' by the discourses surrounding 'life itself'. Resistance to reproductive enhancement and notions of dignity have been explored in this light. The neuroscience of pleasure, subjective experiences of personal meaning and psychoactive substances have been drawn upon as a background for proposals over how research on dying human subjects might take place within appropriate ethical and legal safeguards. My conclusion is to propose a reframing of the good death to include medically enhanced dying as an option.

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