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Focus 9

End-of-Life Decisions, Ethics and the Law

A Case for Statutory Legal Clarity and Reform in South Africa

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A Case for Statutory Legal Clarity and Reform in South Africa

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End-of-Life Decisions, Ethics and the Law

A Case for Statutory Legal Clarity and Reform in South Africa

Willem A Landman

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PREFACE

This is a “Position Paper” rather than an exhaustive academic research paper. Its intention is to put forward an ethical case for end-of-life decision-making legislation. Such legislation would clarify areas of legal uncertainty, most notably in respect of terminal pain management, withholding and withdrawal of life-sustaining treatment (sometimes called “passive euthanasia”), and advance directives (a living will and a durable power of attorney for healthcare).

More controversially, this Position Paper also argues for the inclusion of assisted dying (assisted suicide and voluntary active euthanasia) in a comprehensive end-of-life decision-making bill. It would mean decriminalising what is currently unlawful.

In 1998, the South African Law Reform Commission (then the South African Law Commission) published a report and accompanying draft bill covering the same territory as this Position Paper. It was commissioned by Pres Nelson Mandela, tabled in Parliament in 2000, but officially ignored by the ministry of health. It should serve as a basis for public debate. Analogously, termination of pregnancy (abortion) legislation was, in part, the outcome of such a public debate and legislative process.

Globally, many countries are addressing assisted dying, albeit in different ways. Some have legalised assisted dying and others have set criteria for not prosecuting it.

In South Africa, the debate should be based on the spirit, values and rights in the Constitution, particularly the interpretation of the right to life and its intimate connection with the right to dignity. Our Constitution should shape a moral community that binds us together as citizens, despite the different personal, ethical and religious beliefs we might have in our local communities. A constitutional democracy means, among others, that we resolve our differences about the social arrangement of society by appealing to the Constitution, thus granting others the right to live by their convictions even if we disagree with them.

Ultimately, at issue here is the suffering of people in the end-stage of life. Silence is also a choice for which we are responsible.

This Position Paper was funded by the Ethics Institute of South Africa (EthicsSA). The Addendum shows the results of a scoping survey of South African medical practitioners about end-of-life decision-making.

I wish to thank my colleagues at EthicsSA for their support and encouragement. My thanks also go to colleagues in the medical and legal professions who commented on parts of earlier drafts and helped me to avoid (at least some) indiscretions.

This Position Paper can only be read meaningfully with the help of real-life stories of people who seek assistance with dying, or who wish to assist others with dying without becoming criminals in the process. One such story is that of Prof Sean Davison. He recently returned from New Zealand, where he served a sentence of house arrest for a crime he had not committed. There and here the law fails to recognise appropriately that human life is finite and that the dying process is a natural part of life, which should be dignified and filled with compassion.

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EXECUTIVE SUMMARY

1. Background and Objectives

Life and Death

Dying is a natural and inevitable part of life. Unless we die an unnatural death, we will go through a natural dying process. For some, it will be peaceful and dignified; for others it will be filled with pain, anxiety and suffering. We do not know which it will be.

Biological life is a good that makes all that we treasure possible. But when the life we experience is no longer good, and death no longer bad, but preferable to continued living – irreversibly so – then the role of medicine changes from curing disease and saving or prolonging life to helping usher in death in a way that is compassionate, merciful, and respectful of personal autonomy and dignity.

Unfortunately, we tend to remain silent about the uncomfortable choices we face at the end of life. But developments in medical technology, including our ability to keep people alive, in tandem with our constitutional framework, require that society and the law reflect on our terminal care practices.

The function of the law should be to create an enabling environment for responsible and compassionate terminal care that might, among others, require the potential hastening death.

Legal Clarity and Reform

In South Africa, one significant exception to this silence was the publication of the final report of the South African Law Commission Report, Project 86, dated November 1998 – *Euthanasia and the artificial preservation of life*, Project 86 ("SALC Report") – on law reform in respect of a range of end-of-life decisions. It included a draft bill, titled the *End of Life Decisions Act 1998*. The report had been commissioned by the then president, Mr Nelson Mandela, following an approach by SAVES, a living will society. It was tabled in Parliament in 2000 and for over a decade the report gathered dust on the desk of the then minister of health, Dr MantoTshabalala-Msimang.

The immediate objective of this Position Paper is to contribute to the public debate about end-of-life decision-making, specifically around the aims and content of the SALC Report, as is fit and proper in a constitutional and participatory democracy, such as ours. It is therefore not primarily aimed at an academic audience.

Ultimately, the outcome of the public debate should be the tabling in Parliament of a comprehensive end-of-life decision-making bill, as was the intention with the 1998 draft bill. This would be no different from the legislative process in respect of the termination of pregnancy (abortion).

Legislative change would involve people's deep-seated ethical beliefs about the value of life, the purpose of suffering, and shortening life. Although it is necessary to discuss the ethics of end-of-life healthcare decision-making, we know that such ethical disagreements inevitably lead to an impasse or stalemate about ultimate values. To resolve this, we need to find common ground in the spirit, values and rights embodied in the Constitution.

The challenge, therefore, is not one of reaching *agreement* about the ethics of end-of-life decision-making practices, but to make the ethical case for *legalising* those practices. And this may require either making

existing law *clearer* or, more controversially, initiating legal reform by *legalising* practices that are currently unlawful.

In essence, in a constitutional democracy, such as ours, there is an ethical case to be made for legal clarity and reform in respect of end-of-life decision-making, relating to the need to resolve an ethical impasse or stalemate about social practices that straddle the border between the interests of the individual and interests of the state.

Four End-of-life Decision-Making Practices

This Position Paper identifies and discusses four end-of-life decision-making practices, each recognising an *individual moral right* of persons in the terminal phase of dying. Each of these moral rights corresponds with a *moral obligation* of interested parties, such as caregivers, family, and the state.

These moral rights and obligations need to be recognised appropriately in law, and this requires greater legal clarity, but also legal reform. The exact legal status of the following three practices – each involving an underlying moral right – requires greater *statutory legal clarity* to enable the best possible healthcare for the dying:

- Terminal pain management (Section 2) – the right to be free from unnecessary suffering;
- Withholding and withdrawal of potentially life-sustaining treatment (sometimes referred to as "passive euthanasia") (Section 3) – the right to a natural death; and
- Advance directives (Section 4) – the right to future control over one's body.

More controversially, this Position Paper argues for statutory legal reform decriminalising the currently unlawful practice of:

- Assisted dying (Section 5) (the umbrella term used here for assisted suicide and voluntary active euthanasia) – the right to assisted dying.

A key question is whether decriminalising assisted dying would be consistent with – or perhaps even required by – the bill of rights in the Constitution, particularly the right to life.

2. Terminal Pain Management

Appropriate and adequate *terminal pain management* providing comfort care to a patient suffering from a terminal disease *and* whose death is imminent (who is in a terminal phase or end-stage of a terminal disease) *may* have the secondary effect of hastening death. Potentially, this exposes medical practitioners to criminal and civil liability.

Survey of medical doctors' attitudes:
Pain management and comfort care

In a 2011 scoping survey of South African medical practitioners conducted for this Position Paper (see Addendum at the end of this report), respondents were asked two questions about pain management and comfort care. When asked whether inadequate administration of pain medication was due to *fear of hastening a patient's death*, 54% strongly agreed and agreed, 31% disagreed, while 15% were neutral. When asked whether inadequate pain medication was due to *fear of criminal prosecution for hastening a patient's death*, the responses changed to 39% (strongly agree and agree), 40% (disagree) and 21% (neutral), respectively.

This indicates that under-treatment of pain is a serious problem, at least in part informed by fear of criminal prosecution for hastening a patient's death in an effort to manage pain.

The Need for Legal Clarity

Consequently, there is a need for *legislative clarity* that ensures adequate terminal pain management according to the standard of care for medical practice appropriate in the circumstances. This could be ensured by an honest application of the doctrine of double effect, legitimising the

possible shortening of life if that is the foreseen but unintended outcome of managing terminal pain and suffering appropriately.

In its draft legislation, the SALC Report proposed a legal provision to the effect that if a dosage of medication is inadequate to relieve pain or distress, a medical practitioner or nurse may increase the dosage with the object of relieving that pain or distress, even if the secondary effect is a shortening of the patient's life. Certain formalities are required, such as prescribed record-keeping.

3. Withholding and Withdrawal of Potentially Life-sustaining Treatment

When a person is in the end-stage of a terminal disease, certain treatments may be inappropriate because they are futile, of no benefit to the patient, or no longer achieve their intended goal. Responsible healthcare requires the *withholding or withdrawal of such inappropriate treatment even though the treatment might be potentially life-sustaining* (sometimes called "passive euthanasia", a term avoided in this Position Paper save for terminological clarification).

Refusal of treatment should be a decision made by either a *competent* person, or an *incompetent* person's substitute decision-maker, in consultation with the attending medical practitioner. The ethical considerations of personal autonomy and well-being require that a patient's refusal of treatment be respected.

The Need for Legal Clarity – Competent Persons

Withholding and withdrawal of potentially life-sustaining treatment is an area of great uncertainty in need of *explicit legal clarification*, for reasons such as the following: medical practitioners need to contend with a range of quite different clinical cases; interested decision-making parties may have potentially conflicting motives and opinions; and with the death of the patient the decision becomes irreversible.

Explicit statutory recognition of the moral right of *competent* persons to refuse life-sustaining treatment by means of either contemporaneous or advance-directive instructions would amount to the *recognition of a legal right to a natural death*. The Constitution recognises the right to autonomy or self-determination of competent persons. The *National Health Act 2003* requires consent for all medical treatment, and permits refusal of a service that might result in death.

But current statutory provisions – confirmed by our case law – are tucked away in general provisions about informed consent being required for all treatment. End-of-life decision-making legislation should remove any residual uncertainty by clearly stating that:

- It is lawful to refuse potentially life-sustaining treatment, provided certain conditions are satisfied;
- There is no legally relevant difference between the withholding and the withdrawal of potentially life-sustaining treatment when the standards of responsible medical practice are observed;
- The patient does not need be terminal;
- Artificial nutrition and hydration are medical treatment;
- The refusal does not need to be in writing;
- Medical practitioners are obliged to respect a refusal of treatment; and
- Should medical practitioners do so responsibly or according to the standard of care for medical practice, they would be immune from criminal and civil liability.

The legal position of mature or competent *minors* refusing potentially life-sustaining treatment should also be clarified.

The SALC's draft bill is a good place to find guidance on how to formulate such a statutory legal provision for *competent* persons to refuse potentially life-sustaining treatment contemporaneously.

The Need for Legal Clarity – Incompetent Persons without an Advance Directive

The Constitution recognises the inherent dignity of every person and to have that dignity respected and protected. In respect of *incompetent persons without an advance directive*, this right to dignity must be exercised by a substitute decision-maker. The *National Health Act 2003* provides for family members or others to act as substitute decision-makers on their behalf.

The problem, however, is that this barebones provision for substitute decision-making on behalf of a patient forms part of general statutory legal provisions about the requirement of informed consent for healthcare decisions. Quite understandably, medical practitioners may feel uncertain, or fear litigation, if they were to withhold or withdraw potentially life-sustaining treatment from a patient when directed to do so by a substitute decision-maker. They may:

- Fear that a decision that would hasten death may be imprudent, may be made by a compromised substitute, or the like;
- Be uncertain about the powers of the substitute, or about formalities that might be required;
- Regard the treatment demanded by the substitute as futile and thus inappropriate; and
- Not know whose instructions should prevail if there were more than one substitute (say, two children of the patient) and these substitutes disagree.

Ideally, a substitute should take the place of the patient in all respects, and their decisions should be respected as if they were the patient's own, even if they are potentially life-shortening. Medical practitioners should not have a residual fear that the substitute's decision is not "really" that of the patient. If a competent person may give an advance-direction instruction declining potentially life-sustaining treatment in possible future but specified circumstances in which they might find themselves, then that person's legitimate substitute should be em-

powered to make that very same kind of decision, provided, of course, that the decision meets recognised standards or criteria for responsible decision-making.

It follows that *medical practitioners should not be obliged to follow the instructions of substitute decision-makers if the goal of the treatment is unattainable, futile, or of no benefit, and thus inappropriate*. Typically, such cases involve demands that "everything should be done" regardless of the futility of the treatment and the resources required. Provision should therefore be made for medical practitioners to *decide unilaterally to withhold or withdraw* potentially life-sustaining treatment if the treatment goal is unattainable, including decisions about seriously defective newly born infants.

Incompetence and Complexity

There are different *forms of incompetence*, all of which render one totally and irreversibly incapable of decision-making. In respect of all of these, potentially life-sustaining treatment would be inappropriate because it would be unnecessary and futile. To eliminate uncertainty and provide protection, the law should refer explicitly to persons who:

- Are clinically dead;
- Are in a permanent vegetative state (PVS);
- Have large-scale, irreversible lack of higher brain (cortical) function and therefore severe cognitive impairment, enabling only rudimentary awareness; and
- Are severely defective newly born infants (neonates).

In addition, it may also be desirable to formulate broad legal guidelines about the relevance of *depression* for the determination of a patient's competence to make end-of-life decisions.

There should also be statutory legal clarity about *how decision-making should proceed* in respect of incompetent persons without advance directives, with consensus among surrogate decision-makers and attending medical practitioners being the ideal. In the absence of such

consensus, attending medical practitioners should receive immunity from prosecution for *unilaterally* withholding or withdrawing potentially life-sustaining treatment provided that (1) the healthcare requested by the substitute decision-maker runs counter to responsible standard-of-care treatment, and is therefore inappropriate and futile in the circumstances, and that (2) adequate comfort care is not compromised. Moreover, the law should recognise that administering artificial nutrition and hydration is a form of medical care that may be withheld or withdrawn, accompanied by appropriate comfort care.

Any law aimed at providing greater clarity, may need to mention specific withholding and withdrawal options. In addition to artificial nutrition and hydration, there are do-not-resuscitate (DNR) orders – where the standard of care for medical practice is to perform cardio-pulmonary resuscitation (CPR) in the absence of a valid medical practitioner's order to withhold it – intravenous (IV) fluids, nasogastric (NG) tubes, and the like.

Routine recourse to the courts to decide on appropriate treatment or to settle disagreements about appropriate care should be avoided. Given irreversible, total, or almost total, lack of consciousness, decisions about withholding or withdrawing potentially life-sustaining treatment should be left to substitute decision-makers and attending clinicians.

The SALC Report clearly expresses the need for legal reform in respect of the withholding and withdrawal of potentially life-sustaining treatment from incompetent patients without advance directives.

4. Advance Directives

Any competent person may foresee the possibility of becoming incompetent when they enter the terminal phase of the dying process, and may wish to control their healthcare decision-making as they are able to do when they are competent. Advance directives are designed to enable

competent persons to express their preferences and give instructions about such possible future situations.

The ethics of advance directives is merely an extended application of the ethical values of autonomy, well-being, and respect for human dignity that find expression in contemporaneous end-of-life decision-making by competent persons.

The Need for Legal Clarity

The current legal position is set out in the *National Health Act 2003*. *The provisions in our law regarding advance directives, although a step in the right direction, are inadequate.* It would help to use the accepted terminology for the two types of advance directives, namely, 'living will' and 'durable power of attorney for healthcare' (or just 'power of attorney'), but legal uncertainty goes deeper than mere terminology.

A Living Will

The Act makes provision for a person to refuse a health service "expressly, impliedly or by conduct". *This implies indirectly that a living will which refuses potentially life-sustaining treatment must be taken into account by a medical practitioner*. The Act is correct to conceptualise a living will as having a narrow focus, namely, a *refusal* of potentially *life-sustaining* treatment.

However, it should not be necessary to *infer* a living will from one phrase in the section of an act that deals with informed consent in general. A living will should be explicitly recognised, and related issues surrounding it should be addressed – such as:

- Its purpose and scope;
- Its format and minimum formalities;
- Whether it may in any circumstances be overridden by family or medical practitioners; and
- Whether someone acting on it is immune from criminal and civil prosecution.

A Durable Power of Attorney for Healthcare

The Act also allows for a second type of advance directive – the appointment of a substitute healthcare decision-maker. Any person can "mandate" another person in writing to grant consent for healthcare decisions on their behalf should they become unable to do so, and the Act provides for a priority list of family members and others who may grant such consent in the absence of an explicit, written mandate.

As with a living will, there is a need to clarify the legal status of a *durable power of attorney for healthcare*. Importantly,

- Would the "health service" to which the Act refers include health services which could, if withheld or withdrawn, potentially hasten death?
- Would there be any circumstances in which a substitute's decision could be overridden by family or medical practitioners, provided it complies with other laws?
- What if the attending medical practitioner has good reason to believe that the treatment demanded by the substitute is futile and therefore inappropriate?
- What if the application of the Act means there are two substitute decision-makers – for example, two children – and they disagree about the treatment their parent should receive?
- And would a substitute and medical practitioner be immune from civil and criminal liability for medical negligence, provided decisions are responsible and in accordance with the standard of care for medical practice?

Following proper statutory recognition, the *practical challenges* of advance directives would need to be addressed. For example, people would need to be educated about the purpose and benefits of advance directives. Extensive communication would be needed on how to complete advance directives, where to lodge them so that they would be available when needed, and their availability in acute-care settings as well as in long-term care facilities.

The SALC Report unequivocally supported statutory recognition of advance directives, provided that compliance with the wishes set out in the document would not be unlawful. It did not favour rigid legal requirements. The Report underlined the need to provide legal protection for medical practitioners, and others acting under their direction, against civil and criminal liability if potentially life-sustaining treatment was suspended. It also supported a conscience clause for medical practitioners wishing to opt out. In addition, it held that a living will should only be recognised as valid and legally enforceable in so far as it requested the withholding or withdrawal of life support, not the active ending of life.

Survey of medical doctors' attitudes: Usefulness of advance directives

In the 2011 scoping survey of South African medical practitioners, a vast majority of 75% agreed that advance directives (living wills and powers of attorney for healthcare) assist to clarify patients' wishes regarding treatment at the end of life or when incompetent, while only 12% disagreed. One could expect this positive response to rise, should legislation be passed to clarify outstanding issues, accompanied by a public education campaign.

5. Assisted Dying – Assisted Suicide and Voluntary Euthanasia

In this Position Paper, the terms 'assisted dying' and 'assistance with dying' are used as umbrella terms for both 'assisted suicide' (including 'doctor-assisted suicide') and 'voluntary active euthanasia' (or simply 'voluntary euthanasia'). The term 'euthanasia' is not used, unless for terminological clarification, as is the case here.

Voluntary Choice to End Life

For a discussion of both the ethics and the law of assisted dying, it is crucial to bear in mind that with assisted dying we are dealing with *free*

or voluntary choices by competent persons to end their lives. No-one is forced, coerced or unduly influenced to make that decision. So, any talk of "deciding for (competent) others" that they should die, is totally out of place in this discussion.

Assisted Dying is Unlawful

Both forms of assisted dying – assisted suicide and voluntary (active) euthanasia – are unlawful in South Africa. Legal reform would mean legalising what is currently unlawful. This Position Paper argues that there is a strong *ethical case for legalising assisted dying* (the ethics of legalising this practice) based on the values and rights in the Constitution. But since assisted dying is such a highly controversial and emotive topic, this Position Paper also discusses critically *some key ethical arguments for and against assisted dying* (the ethics of this practice).

Survey of medical doctors' attitudes: The ethics of assisted dying (doctor-assisted suicide and active voluntary euthanasia)

In the 2011 scoping survey, South African medical practitioners expressed their views on the ethics of assisted dying (assisted suicide and voluntary euthanasia). Two out of every five respondents (40%) either affirmed that, or were uncertain whether, they would *administer a lethal drug upon request* (perform voluntary active euthanasia). This percentage rose marginally to 43% when respondents were asked whether they would *provide the means to enable assisted suicide*. This is an indication that respondents believe the two forms of assisted dying – doctor-assisted suicide and voluntary euthanasia – to be, ethically speaking, similar or identical.

Very significantly, however, when respondents were asked whether they could imagine a future illness bad enough that *they themselves* would commit assisted suicide, or would ask a colleague to perform voluntary euthanasia on *them*, this percentage rose by roughly 50% to almost two-thirds (63%).

Although ethical arguments *for* assisted dying appear to be stronger, arguments *against* this practice need to be taken seriously. The end result is an ethical impasse or stalemate. Escaping from it would require us to *find common ground on a level other than our different, basic, ethical and religious beliefs, by interrogating the content of our common constitutional values and rights, and by asking what these require from us in our constitutional democracy.*

Constitutional Interpretation Needed to Resolve Ethical Stalemate – the Right to Life

Could our constitutional rights be interpreted in such a way that assistance with dying – assisted suicide and voluntary euthanasia – could, or even should, be decriminalised within clearly defined parameters? There are respected legal academics who contend that the underlying values, spirit and purport of relevant sections of the Constitution would support the introduction of assisted dying in South Africa.

A key constitutional issue revolves around the interpretation – specifically limitation – of the constitutional right to life. The same legal academics argue that, in the case of termination of pregnancy, the right to freedom of choice and the right to bodily integrity are justifiable limitations to any other right that may be infringed by such an act, provided there is compliance with all regulations. The anomaly is that, given a right to life, there is no right to die that would be the equivalent of the right to abortion.

One could also argue that our common-law definitions of criminal offences guiding our case law appear to be inadequate to do justice to the underlying ethical values that inform assistance with dying. They lack the necessary sensitivity for specific circumstances in which persons may wish to claim their right to exercise autonomous choices regarding their suffering and continued life. They leave no legal space for assisting someone to die for their own good, when that is their free and rational preference, without risking criminal or civil liability. There is

insufficient legal recognition of the fact that life may have such a low quality that death becomes the only escape from all-consuming, irreversible suffering.

Three Legalisation Options in the 1998 Draft Bill

The SALC Report offered three legislative options in respect of assisted dying. Option 1 retains the *status quo*, with assisted dying remaining unlawful. Option 2 proposes legalising assisted dying, with the involvement of the patient, the attending medical practitioners and the family in the decision-making. Option 3 also proposes legalising assisted dying, but the decision-making becomes the responsibility of an institutional ethics committee.

The SALC Report favours Option 1. This Position Paper attempts to rebut the SALC Report's arguments against legalising assisted dying, and argues that something akin to Option 2 should become law. This is where the public debate should commence, informed by interpretation of the relevant sections and spirit of the Constitution. The debate should take note of international developments in several countries in the intervening 14 years, since the publication of the SALC Report. Importantly, a number of issues would need *further discussion to settle the boundaries of what would be permissible*, most notably legal safeguards to prevent abuse.

Whatever the different religious, ethical, clinical and legal viewpoints we might have, *a debate about the ethics of decriminalising assisted dying is in essence a debate necessitated by the ethical imperative to interpret fundamental constitutional rights in respect of an area of human need*.

In summary, we have very persuasive ethical and constitutional grounds for debating and seriously considering the inclusion of assisted dying – assisted suicide and voluntary euthanasia – in comprehensive end-of-life decision-making legislation, together with provisions clarifying decision-making on the legal status of terminal pain management,

the withholding and withdrawal of potentially life-sustaining treatment, and on advance directives.

Survey of medical doctors' attitudes: The need for legalising assisted dying (doctor-assisted suicide and active voluntary euthanasia)

In the 2011 scoping survey, South African medical practitioners were asked two questions about the need for legalising assisted dying. When asked whether *doctor-assisted suicide* should be legalised, 51% said no, while 49% strongly agreed, agreed or were neutral. When asked whether *voluntary active euthanasia* should be legalised, these percentages changed to 53% (no) and 47% (strongly agree, agree and neutral) respectively, again indicating that these two practices were regarded as the same.

An overwhelming 81% indicated that assisted dying should only be contemplated when a patient is terminally ill, whereas a significant one in eight (12%) felt that assisted dying does not require terminal illness.

One-third (34%) of respondents indicated that in the course of their medical practice, patients had *requested* them to hasten their death.

In the final analysis, *at issue here is the ethical imperative that law and public policy in the democratic state should establish a responsible balance between respect for personal conscience (individual autonomy) and the pursuit of the public good (state interest).*

1

INTRODUCTION

1.1 Background and Objectives

End-of-life decision-making in South African healthcare has to contend with the absence of adequate certainty about the boundaries of what is legally permissible. Certainly, the variety and complexities of individual cases will never be fully covered by legal provisions that are, of necessity, formulated in general terms.

Still, a clear need exists for the creation of a legal framework within which patients, their families and healthcare professionals will be able to make difficult end-of-life decisions with greater legal certainty and better guidance, thus affording them greater protection, confidence and comfort.

This Position Paper presents an ethical case for legal clarity and reform in respect of end-of-life decision-making – firstly, clarity in respect of what is legal but insufficiently clear, and secondly, reform in respect of what is currently unlawful.

This is not an abstract or comprehensive ethical or legal research paper on end-of-life decision-making. It simply defends the position – admittedly somewhat tendentiously – that such decision-making should be placed on the public agenda, as is fit and proper in a constitutional and participatory democracy, such as ours. Rather than advancing abstract arguments, it seeks to assist in focusing the public debate on issues that should concern us all.

Ultimately, the outcome of the public debate should be the tabling in Parliament of a comprehensive end-of-life decision-making bill. This would be no different from the legalisation process in respect of the termination of pregnancy (abortion).

Medical decisions about life and death are controversial, involving some of our most treasured personal and religious beliefs. Still, controversy does not justify unexamined acceptance of the *status quo*. Indeed, South Africa has a Constitution with a justiciable bill of rights[1] that challenges us to examine existing social practices in a new light. And we have done so in respect of other controversial social practices, such as legalising the termination of pregnancy (abortion)[2] and abolishing capital punishment,[3] both of which probably run counter to majority public opinion.

Uncertainty and lack of legal protection relate to a number of end-of-life decision-making practices, most notably the following:

- *Terminal pain management*: Fear of shortening life, and thus possible civil and criminal liability, informs a tendency to under-treat the pain and suffering of terminally ill patients.
- *Withholding and withdrawal of potentially life-sustaining treatment*: The circumstances in which one may refrain from potentially life-sustaining treatment, by either not commencing it or terminating it once commenced (sometimes referred to as "passive euthanasia"), lack legal clarity, resulting in unnecessary artificial lengthening of life, thus preventing a natural death, for fear of litigation.
- *Advance directives*: Competent persons may give instructions about how their healthcare should be managed – should they become incompetent to decide for themselves – by means of an advance directive, such as a living will or a power of attorney for healthcare

[1] *Constitution of the Republic of South Africa Act, 108 of 1996.*
[2] *Choice of Termination of Pregnancy Act, 92 of 1996.*
[3] The Constitutional Court ruled that capital punishment is unconstitutional and an unacceptable limitation to the right to life (section 11 of the Constitution). See *S v Makwanyane* 1995 2 SACR 1 (CC).

given to a substitute decision-maker. However, advance directives enjoy an uncertain legal status in South Africa.

- *Assisted dying (assisted suicide and voluntary euthanasia)*: With assisted suicide, the proximate cause of a competent person's death is their own voluntary action, but it is made possible when a healthcare professional or other person supplies the necessary means to commit suicide. Voluntary (active) euthanasia occurs when a competent person voluntarily requests assistance with dying and the proximate cause of death is an act by a healthcare professional or other person, for example lethal injection. Such acts are highly controversial and indeed unlawful. But the question remains whether their legal prohibition is ethical and constitutional.

In the late 1990s, we missed the opportunity to review our law in respect of all these end-of-life decisions following the publication by the South African Law Commission ("SALC") of its final report, dated November 1998 – *Euthanasia and the artificial preservation of life* ("SALC Report") – which also included a draft bill on end-of-life decisions, titled *End of Life Decisions Act 1998*.[4] This report had been commissioned by the then president, Mr Nelson Mandela, and covered the whole range of end-of-life decisions, not only the more controversial practices of assisted suicide and voluntary euthanasia.

The report and its accompanying draft bill were tabled in Parliament in 2000 but have been officially ignored over the past 14 years. For a decade, it gathered dust on the desk of the then minister of health, Dr Manto Tshabalala-Msimang. Why this happened, is an open question. Anecdotal evidence suggests that she considered it "medicine for the

[4] South African Law Commission (SALC) Report Project 86: *Euthanasia and the Artificial Preservation of Life*. Pretoria, November 1998.
http://salawreform.justice.gov.za/reports/r_pr86_euthen_1998nov.pdf
The South African Law Commission was subsequently renamed the South African Law Reform Commission.

rich"[5] and thus, presumably, not worthy of legal reform requiring the application of public resources. But everyone, regardless of wealth or social standing, eventually dies, often in unnecessary pain and suffering, and also in public hospitals.

Resources spent on the SALC Report should not go to waste, particularly since the issues addressed in the Report remain with us. Moreover, the world has moved on in the 14 intervening years. Several countries have revisited, or are currently revisiting, their legal frameworks for end-of-life decision-making.

In the final analysis, there are people who suffer unnecessarily and die in an undignified manner. Their wishes appear to count more during their lives than at the end of their lives, when fear, pain and suffering may be at their worst. Often this leads to a feeling of abandonment in their greatest need. Unabated media reports over the years corroborate this – most recently, in December 2011, with the guilty verdict and house arrest in New Zealand of South Africa-domiciled Prof Sean Davison.

The reasons for revisiting the end-of-life issues addressed by the SALC Report are very persuasive. They add up to *an ethical imperative to question the adequacy of our legal framework to govern end-of-life care. Remaining silent on these admittedly uncomfortable issues is also a choice for which we as a society are responsible and should be held accountable.*

1.2 Ethics

Fundamentally, the debate about what is right and good in end-of-life decision-making and care is an ethical one. Underlying each of the four end-of-life decision-making practices is an individual moral right of

[5] Personal communication with a journalist who contacted the minister's office towards the end of her term of office.

persons in the terminal phase of dying. Each of these moral rights corresponds with a moral obligation of interested parties, such as caregivers, family and the state:

- *Terminal pain management* – the right to be free from unnecessary suffering;
- *Withholding and withdrawal of potentially life-sustaining treatment* (sometimes referred to as "passive euthanasia") – the right to a natural death;
- *Advance directives* – the right to future control over one's body; and
- *Assisted dying* (assisted suicide and voluntary active euthanasia) – the right to assisted dying.

An ethical debate about these moral rights and obligations may proceed on two levels,[6] namely:

- The ethics of end-of-life decisions (the ethics of a practice); and
- The ethics of laws about end-of-life decisions (the ethics of legalising a practice).

This Position Paper is primarily concerned with the latter – ethical justification for legislative and public-policy revision and reform regarding end-of-life decision-making that will provide greater legal clarity, thus mitigating the undesirable consequences of the legal and healthcare *status quo*.

But this Position Paper also engages with arguments about the former – the ethics of end-of-life practices and decisions – because deep-seated ethical beliefs and positions inform the content and direction of the debate about the ethics of legal reform.

In essence, *in a constitutional democracy, such as ours, there is an ethical case to be made for legal clarity and reform in respect of end-of-life decision-making, relating to the need to resolve an ethical impasse or stalemate about social practices that straddle the border between the interests of the individual and interests of the state*.

[6] SALC Report, p 94.

1.3 Law

Earl Warren, 14th Chief Justice of the United States Supreme Court, said the following: "In civilized life, law floats in a sea of ethics".[7] Ethics and law both embody standards or norms for good, right and fair conduct, practices and institutions. Only some of our ethical standards or norms are codified or laid down in law.

Beyond the law lies a vast area where the goodness, rightness or fairness of our conduct requires our discretion about, and interpretation of, what is to be done.

Over time, our moral insights, and thus the standards of ethically acceptable conduct, change. Some of these ethical changes are reflected in changes to the law. For example, slavery was universally the norm, but is now illegal everywhere; women had an inferior legal status in global social morality, but, with some exceptions, this is no longer the case; and in certain jurisdictions, attempted suicide used to be a crime.

It would thus be quite natural for the legal position regarding end-of-life decisions to change over time, since it reflects changing underlying ethical insights and understandings, following, for example, advances in medical technology.

This Position Paper starts from the *assumption that our public-policy framework in respect of end-of-life decisions needs to be clarified and, where necessary, substantially reformed to give clearer guidance, protection, and comfort to patients, their families and medical practitioners.* It is unnecessary that routine but agonising decisions are made even more difficult for lack of clarity and fear of being on the wrong side of the law. There is a clear need to create an enabling legal environment within which medical practitioners will be able to assist the dying and their families without fear that the law would intrude where their deci-

[7] http://thinkexist.com/quotation/in_civilized_life-law_floats_in_a_sea_of_ethics/204665.html

sions are based on responsible, standard-of-care, medical judgment and practice.

There are persuasive ethical reasons for reviewing the legal framework within which end-of-life decisions are being made. Apart from universal ethical reasons relating to well-being, autonomy and justice, the justiciable bill of rights in the Constitution contains rights that are ethical claims or entitlements, with corresponding responsibilities. Since some of these rights bear upon end-of-life decisions, we therefore have an ethical duty to reflect upon what the Constitution's requirements in this regard might be.

Constitutionally grounded public policy is non-sectarian, informed by ethical and constitutional values rather than religious belief. Of course, ethics draws from religion, among others, but public policy remains neutral in respect of the articles of faith of specific religions, or religious belief in general.

The key task of this Position Paper is *to put forward reasons and suggestions for statutory legal clarification and reform in respect of four end-of-life decision-making practices*, each with underlying moral rights and obligations, with a view to enabling the best possible healthcare for the dying:

- Terminal pain management (Section 2);
- Withholding and withdrawal of potentially life-sustaining treatment (Section 3);
- Advance directives (Section 4); and
- Assisted dying – Assisted suicide and voluntary euthanasia (Section 5).

Each of these will be discussed as follows:

- An explanation of the meanings of *key terms*;
- A discussion of some of the *ethical considerations* at issue; and
- A description of the *current legal position* and suggestions for *statutory legal clarification or reform*.

2

TERMINAL PAIN MANAGEMENT

Terminal pain management is an end-of-life decision-making practice that recognises the *moral right of individuals in the terminal phase of dying to be free from unnecessary suffering*, as well as the corresponding moral obligation of caregivers, family and the state to respect that right. The law should be clear about the legal status of this right and obligation.

2.1 Terminology

Key terms for a discussion on the ethics and law of terminal pain management are the following:

- '*Suffering*' is a mental response to the experience of either physical pain or mental distress.
- '*Comfort care*' or '*palliative care*' (from the Latin '*palliare*', to cloak) is healthcare directed at preventing, alleviating (reducing) or terminating suffering. It may be administered for curable and incurable diseases, at any stage of the disease, and is therefore a wider concept than terminal care, including hospice care. Comfort care for an incurable disease is *non-curative* care and provides only *symptom (pain, distress) relief* and thus contrasts with '*acute care*', which strives to restore health. Comfort care may involve '*palliative sedation*', that is, "intermittent and continuous as well as superficial

[light] and deep sedation"[1], '*sedation*' being the allaying, assuaging, or soothing of pain by means of a narcotic drug or anxiolytic. A narcotic drug, such as morphine, is an overall sedative or central depressant that produces drowsiness.

- It is notoriously difficult to define when a patient is '*terminal*'. Efforts to do so by means of the time the patient is expected to live (for example, no longer than six months) are inaccurate and do not take into account the different trajectories – ups and downs – of different disease progressions. One may have a *terminal disease*, a disease that would eventually kill, *without yet being terminal* in the sense of having reached *a point of no return where death is imminent*, death being hours, days, or perhaps a week or two away. Of course, this understanding of 'terminal' is also in terms of time, but *the time before the person is expected to die is very short and intimately connected to a point of no return*.
- With terminal patients, comfort care may involve '*potentially life-shortening symptom relief*', where the administration of a sedative to relieve pain symptoms has the potential side-effect of suppressing respiration. Whether a sedative may shorten life, depends on different variables, such as the stage of the disease or the dosage of the sedative. At the one extreme, it is possible to hasten death with a dosage strong enough so that the patient dies, as it were, at the end of the needle; at the other extreme, the sedative simply calms the patient while it is impossible to know whether it shortens life or whether the patient might have died anyway without the sedative at more or less the same time.
- Such potential life-shortening symptom relief may be in the form of '*terminal sedation*', that is, "potentially life-shortening deep and

[1] Udo Schüklenk *et al*: End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert panel in End-of-Life Decision-Making. *Bioethics*, Volume 25, Number S1, 2011, pp 1-73, at p 6.

continuous sedation intentionally combined with the cessation of [artificial] nutrition and hydration."[2]

- Some invoke the '*doctrine of double effect*' to justify ethically the intended direct consequence of administering medication – namely relief of suffering – while a hastened death is foreseen as an indirect but unintended and inevitable consequence.

2.2 Ethical Considerations

Traditionally, end-of-life comfort care decisions arose with the management of end-stage cancer. But, there are several chronic diseases that pose a range of questions for end-of-life decision-making, such as dementia, congestive heart failure, chronic obstructive pulmonary disease, and acute chronic depression that fails to respond to treatment.

Whatever the disease, end-of-life decision-making does not detract from the need to provide appropriate and adequate comfort care. We strive to relieve suffering throughout our lives, and it should be no different at the end of life. The Health Professions Council of South Africa (HSPCA) confirms that a healthcare provider has a duty to assist a dying person to alleviate suffering in the terminal phase of illness.[3]

Some argue that suffering has a purpose, and therefore should be endured. Interestingly, this argument is seldom, if ever, advanced when *non-terminal* suffering is at issue; only when ending suffering could possibly hasten the death of a terminal patient. Whatever metaphysical or religious reasons may be advanced for the moral imperative to endure suffering – for example, that it ennobles or purifies the soul, or helps spiritual growth – others are morally entitled to reject them, autonomously preferring to be freed from suffering.

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[2] See footnote 8.

[3] Health Professions Council of South Africa (HPCSA): *Guidelines for the Withholding and Withdrawing of Treatment, Booklet 12,* Pretoria, May 2008, Clause 1.3, p 1.

Under-treatment of terminal patients' suffering, induced by pain and consequent distress, is a worldwide phenomenon and it is no different in South Africa. Two possible explanations for this tendency are, firstly, our inability truly to understand and identify with the suffering of others (since one person cannot experience another's suffering and suffering cannot be directly measured but is inferred from bodily signs) and, secondly, the fear among medical professionals of doing harm, including hastening death, which would expose them to legal liability.

Survey of medical doctors' attitudes: Pain management and comfort care

In a 2011 scoping survey of South African medical practitioners conducted for this Position Paper, respondents were asked two questions about pain management and comfort care.[4] When asked whether inadequate administration of pain medication was due to *fear of hastening a patient's death*, 54% strongly agreed and agreed, 31% disagreed, while 15% were neutral. When asked whether inadequate pain medication was due to *fear of criminal prosecution for hastening a patient's death*, the responses changed to 39% (strongly agree and agree), 40% (disagree) and 21% (neutral), respectively.

This indicates that under-treatment of pain is a serious problem, at least in part informed by fear of criminal prosecution for hastening a patient's death in an effort to manage pain.

So, a key ethical issue regarding comfort care of terminal patients is under-treatment of suffering caused by pain and distress, constituting inadequate terminal care management. There is no ethical justification for unnecessary suffering. *Professional medical care requires responsible, adequate management of pain-induced suffering.*

Importantly, however, *even the best conceivable pain management and comfort care do not remove the need for an ethical and legal debate*

[4] See the Addendum at the end of this Position Paper, Figures 9 and 10.

about the more controversial forms of assisted dying, namely assisted suicide and voluntary euthanasia (discussed in Section 5, below). The argument that pain medication, coupled with a conventional dosage of sedative, would keep patients asleep until they die a natural death[5], ignores patients' legitimate preferences not to die in a state of deep palliative sedation or terminal sedation, or in circumstances they regard as undignified. Comfort care would not, for some at least, enable them to die a dignified death free from suffering if it ignores or overrides their autonomous choice to have control over the time and manner of their death.

This point is mentioned here because some believe that good comfort care makes the whole debate about assisted suicide and voluntary euthanasia a dispensable academic exercise. This disregards or diminishes the importance of personal autonomy and is based on a misconception of personal autonomy as selfish and anti-communitarian.[6]

Moreover, the SALC Report found "that the fear that incentives for providing palliative care would be diminished if assisted suicide and active euthanasia were decriminalised, were unfounded."[7] The SALC Report's draft bill guards against this by making assisted dying conditional upon there being no other way to release a person from suffering. Failing this condition would be a breach of the law.

Still, any debate about assisted suicide or voluntary euthanasia (Section 5, below) should proceed from the assumption that the most appropriate comfort care possible is non-negotiable in all end-of-life decision-making.

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[5] Selma Browde: Good Palliative Care Removes Need for Euthanasia, *Business Day*, 25 November 2011. See also SALC Report, p 100.

[6] Jonathan Victor Larsen: Death with Integrity, *South African Medical Journal* (SAMJ), Volume 101, Number 11, November 2011, pp 781-782. Also see Section 5.2.1.1, below, and accompanying footnote 55.

[7] SALC Report, pp 105.

2.3 A Case for Legal Clarity

In so far as the under-treatment of suffering is the result of uncertainty about the limits and consequences of terminal pain management, and therefore fear of civil and criminal liability, the law guiding such care should be clarified. Pain management, with its possible attendant risks of hastening death, is standard medical practice. The law, apart from its already existing controls on medical malpractice, should not inhibit terminal pain management by placing it under threat of prosecution for doing the right thing on the basis of responsible clinical judgment.

Since the absence of legal clarity evidently contributes to the under-treatment of pain, the legal position in this regard should be clarified. Comfort care that meets the standard of care for medical practice should be explicitly divorced from civil and criminal liability, even if such care also happens to hasten death.[8] This could be done by explicit legal recognition of the doctrine of double effect in respect of end-of-life decisions. The standard of medical cpractice should be decisive, because it is a matter of clinical judgment rather than a legal matter. Law should create an enabling and protective environment for medicine to do what it should.

The SALC Report did just that in its draft legislation when it proposed a legal provision to the effect that if a dosage of medication is inadequate to relieve pain or distress, a medical practitioner or nurse may increase the dosage with the object of relieving that pain or distress even if the secondary effect is shortening the patient's life. Certain formalities are required, such as prescribed record keeping.[9]

In summary, *legal clarity requires a statutory provision that allows for responsible clinical decisions regarding terminal pain management.*

[8] Submissions to the SALC, SALC Report, p 53 (at 4.44). Also see Melodie Slabbert: *Medical Law – Suppl. 65: South Africa:* Alphen aan den Rijn: Wolters Kluwer, March 2011, p 141.
[9] SALC Report, pp 8-9.

Potentially life-shortening symptom relief, if the intention is to ease pain, should be explicitly legalised. Responsible, standard-of-care medical practice should not be the domain of the courts. Failure to adhere to the standard of care for medical practice – medical negligence – is the business of the law.

3

WITHHOLDING AND WITHDRAWAL OF POTENTIALLY LIFE-SUSTAINING TREATMENT

Withholding and withdrawal of potentially life-sustaining treatment is an end-of-life decision-making practice that recognises the *moral right to a natural death of individuals in the terminal phase of dying*, as well as the corresponding moral obligation of caregivers, family and the state to respect that right. The law should be clear about the legal status of this right and obligation.

3.1 Terminology

Key terms for a discussion on the ethics and law of withholding and withdrawal of potentially life-sustaining treatment are the following:

- '*Withholding potentially life-sustaining treatment*' means to refrain from commencing treatment that has the potential to lengthen or sustain a person's life, for example by providing cardiopulmonary resuscitation (CPR) for a person having a cardiac arrest, or renal dialysis for a person in renal failure, or antibiotics for an acute, life-threatening infection.
- '*Withdrawal (cessation) of potentially life-sustaining treatment*' means stopping treatment, previously started, that has the potential to sustain a person's life, for example by disconnecting a person from life support, such as a ventilator.

- Withholding and withdrawal of potentially life-sustaining treatment are sometimes referred to as '*passive euthanasia*', a term avoided in this Position Paper.
- '*Competence*' means the capacity of persons to understand, reason about, make decisions, and communicate about their healthcare in an end-of-life situation. Competence is task-specific, thus one may be competent to choose one flavour of ice cream over another, but incompetent to make an irreversible life-changing decision. Competence is relative to a range of variables, such as knowledge and wisdom, mental development and mental degeneration.
- A '*substitute, proxy or surrogate healthcare decision-maker*' is a person who is ethically or legally empowered to make healthcare-related decisions on behalf of a patient who is temporarily or irreversibly incompetent to make their own healthcare decisions. The substitute makes healthcare decisions in the stead of the patient, on the basis of appropriate standards or criteria in the circumstances, such as:
  - *Subjective standard* – from what one knows about the patient one infers what the patient actually would probably have wanted;
  - *Substituted judgment standard* – by imaginatively placing oneself in the position of the patient one deduces what the patient probably would have wanted; and
  - *Best-interest standard* – from the available options, one chooses the treatment option with the highest net benefit, using objective standards.
- When a decision to withhold or withdraw life-sustaining treatment is made without the knowledge of the patient or the patient's substitute decision-maker, it amounts to *unilateral refusal (withholding or withdrawal) of treatment*, for example, writing a do-not-resuscitate (DNR) order on a patient's hospital chart with or without consulting the patient or the patient's surrogate decision-maker.

3.2 Ethical Considerations

In this Position Paper the terms 'refusal', 'withholding' and 'withdrawal' of potentially life-sustaining treatment are used, rather than the term 'passive euthanasia', where the term 'passive' indicates that the action performed by the person who withholds or withdraws treatment is an omission (passive) rather than an act or commission (active).

For human beings, as for other creatures, there is a necessary connection between life and good. Biological life is the precondition for all that is experienced as good. This connection may, however, be broken, so that the life we experience, everything considered, is no longer good (a benefit, desirable, or worth living), *or* that the good that does remain is outweighed by the bad for the one whose life it is. For example, biologically human life irreversibly devoid and incapable of consciousness is no longer a good; or in a human life saturated by pain and suffering the bad might outweigh the good.

Given this human condition, persons find themselves in situations where decisions need to be made about the withholding or withdrawal of potentially life-sustaining treatment. Such decision-making is either by persons who are competent to make such decisions (Section 3.2.1, below), or on behalf of persons who are no longer, or have never been, competent to do so (Section 3.2.2, below).

3.2.1 Competent Persons

According to the *ethical principle of autonomy or self-determination*, competent persons have a moral right to make decisions that are their own, reflecting their own values and preferences. This would include decisions about their healthcare, whether routine or in end-of-life situations. More specifically, in end-of-life situations, patients may validly refuse potentially life-sustaining treatment, choosing that such treatment be withheld or withdrawn. And they would do so because they themselves judge that the bad of life decisively outweighs the good. Thus,

one may autonomously judge a life consumed by suffering and stripped of dignity not worth living, and that judgment deserves respect.

Our autonomy is embedded, and indeed constituted, in a network of relationships. Some rely more heavily on others in making their decisions, including end-of-life decisions. In a less individualistic, more communitarian culture, individuals may view their decisions as expressions of a collective will. But even in an extreme communitarian culture it is improbable that decision-making is completely heteronomous such that a person's locus of decision-making is completely outside themselves, subsumed, in some robotic fashion, under the will of others or the collective. There will always be some space for autonomous preferences, judgments and decision-making about what is right and wrong, good and bad in general and, more specifically, about one's continued life and healthcare.

In short, *the assertion of our autonomy that leaves space for decision-making that is ultimately one's own is not dismissive of community and family bonds, and thus the influence of the will of others in our lives.*[1] (See Section 5.2.1.1, below.) Personal autonomy comes in degrees. Ethics requires that it be respected in whatever degree it comes.

The recognition of autonomy means that competent persons should be allowed to make their own healthcare decisions, even if their lives are shortened as a consequence. Our *well-being* is not simply an objective matter; it also has a subjective component. Well-being relates to *objective facts* about our health as well as our *subjective experience or sense* of our health and dignity. The principle of autonomy recognises our moral freedom to make judgments about the subjective element of our well-being, including valid refusals of potentially life-sustaining treatment.

[1] Jonathan Victor Larsen: *op. cit.*

Apart from contemporaneous decisions, the principle of autonomy also extends to competent individuals expressing preferences and giving instructions regarding their treatment in possible or foreseen scenarios where they may no longer have the ability to make autonomous decisions. *Advance directives* are the subject matter of Section 4, below.

Competence in respect of valid refusals of potentially life-sustaining treatment is not confined to adults only. *Mature minors* may be competent too, for example a 12-year-old child who has been in and out of cancer wards over many years. Chronological age alone is an unreliable indicator of competence.

To summarise: the ethics of withholding and withdrawal of potentially life-sustaining treatment from *competent* patients centres round a recognition of their autonomy. *Their autonomous decisions involve judgments about their well-being, welfare or interests.* Since well-being has an objective element, clinicians' judgements are needed to determine the objective facts. But the subjective element of well-being relates to patients' experience and assessment of their well-being, and their autonomous choice to decide about withholding or withdrawal of potentially life-sustaining treatment. Respect for autonomy means recognising the right of others to judge their own well-being, thus respecting their human dignity.

3.2.2 Incompetent Persons without Advance Directives

Turning to *incompetent, but formerly competent, persons without advance directives*, the ethics of decision-making about the withholding or withdrawal of potentially life-sustaining treatment would be determined by the appropriateness of the *goal* the treatment is supposed to achieve. If the goal of treatment is unattainable, then treatment in pursuit of that goal is futile or without benefit. Treatment that makes a worthwhile life possible, brings about a benefit. *But merely restoring vital functions while no worthwhile life is possible, is futile, achieving an effect that is no benefit.*

For example, merely continued biological life – with no prospect of any conscious life – of a patient in a permanent vegetative state (PVS), is treatment with an *inappropriate* goal. Thus, withholding antibiotics from a PVS patient for treating a life-threatening infection would be ethically justified – even if death is the consequence – since meaningful or worthwhile life is impossible, which is an *intrinsic* ethical justification. Life-sustaining treatment would be *futile* since the patient cannot derive any benefit from it in terms of a meaningful or worthwhile life. An independent, *extrinsic*, ethical justification for withholding antibiotics would be that resources could be utilised more effectively to achieve an appropriate goal.

Likewise, attempting to restore a patient with severe and irreversible brain damage or degeneration to conscious life may be an *unattainable* and therefor *inappropriate* objective. Thus, discontinuing (withdrawal of) ventilator support, after an initial period to ascertain the extent of the brain injury or degeneration, would be ethically justified, for the same reason as with a PVS patient.

We recognise the legitimacy of the practice whereby healthcare decisions may be made by *substitute decision-makers* on behalf of formerly competent patients, thus transferring autonomous decision-making authority to someone else who has the capacity and moral standing to do so. Substitute decision-making would include valid refusals of routine as well as life-sustaining treatment. The different standards for substitute decision-making would kick in sequentially: if the subjective standard cannot be applied for lack of adequate information on which to base a judgment about the patient's probable wishes, the substituted-judgment standard should be used but could, in turn, be replaced by the best-interest standard, again for lack of adequate information.

Withholding or withdrawing potentially life-sustaining treatment from *seriously defective newly born infants – who have never been, and would never become, competent* – requires substitute decision-making

by their parents in consultation with attending medical practitioners. Such decisions should be based on clinical facts about the seriousness of the condition, prospects of recovery, envisaged quality of life and the like, and should be tested against the *best-interest standard* for substitute decision-making.

Who should act as substitute decision-makers on behalf of incompetent patients without advance directives? Ideally, there should be a consensus decision among substitute decision-makers (such as close family members) and attending medical practitioners.

How should substitute decision-makers decide on behalf of an incompetent person? They should be guided by an appropriate and attainable treatment goal as well as by appropriate interventions necessary to achieve that goal. Unfortunately, matters are not always that simple, and the death bed often becomes the site for making amends for past neglect or even extending life to enable inheritance battles to be settled.

There are clearly definable situations where strong ethical arguments – relating to futility of treatment and irresponsible use of scarce healthcare resources – can be advanced in favour of *unilateral decision-making*, thus overriding decisions by substituted decision-making in pursuit of inappropriate or unattainable treatment goals, even if this would hasten death.

Substitute decision-makers should be consulted and persuaded, but they lack moral justification to insist on treatment with an inappropriate or unattainable goal. Consider Case Study 1 of an anonymised real-life situation.

Even if Mr X's family could afford to pay for his treatment when his healthcare insurance cover is exhausted, the ICU bed that he occupies may be required for someone with excellent health prospects but who needs to be pulled through an acute crisis. Surely, there is an overwhelmingly strong ethical case for attending medical practitioners to overrule the decision of the family or substitute decision-makers that

"everything be done" for the patient. Moving the patient to an ordinary ward or a step-down comfort-care facility would shorten his life, but would be the right thing to do.

Case Study 1: Irreversibly non-responsive octogenarian patient in ICU

Mr X is an octogenarian male patient who is for all practical purposes non-responsive to outside stimuli. He only shows occasional signs of rudimentary consciousness, his condition appears irreversible, and he shows no signs of improvement. He has been occupying a neurology intensive care unit (ICU) bed for two years. He receives multiple daily medications and is given physiotherapy daily, but his limbs remain rigid. He is treated aggressively with antibiotics whenever he contracts an infection. Three specialists visit him on an almost daily basis.

Mr X's family wants everything done for him. His top healthcare plan has paid all his medical bills, amounting to over R12 million.

Lack of understanding of end-of-life decision-making options should be managed proactively by appropriately informing patients and family members upon the patient's admission to a healthcare facility.

3.3 A Case for Legal Clarity

The law should recognise, and create the space for, ethically responsible decision-making in respect of withholding or withdrawing potentially life-sustaining treatment from competent and incompetent persons. It is an area of great legal uncertainty in need of explicit legal clarification, for reasons such as the following: medical practitioners need to contend with a range of quite different clinical cases; even healthcare decision-makers who act according to the relevant standard of care for medical practice nevertheless run the risk of criminal or legal action; interested decision-making parties may have potentially conflicting mo-

tives and opinions; and with the death of the patient the decision becomes irreversible.

Decisions about the withholding or withdrawal of potentially life-sustaining treatment are made by competent patients (Section 3.3.1, below), or on behalf of incompetent patients (Section 3.3.2, below).

3.3.1 Competent Persons

The Constitution recognises the *right to autonomy or self-determination*, specifically the right to freedom and security of the person (section 12) – which includes the right not to be deprived of [one's] freedom arbitrarily and without just cause and the right to security of and control over [one's] body – and the right to privacy (section 14). Treatment that keeps competent persons alive against their will would override their personal autonomy.

First, legislation should state explicitly that any *competent* person has the right to decide *contemporaneously* that potentially life-sustaining treatment should be withheld or withdrawn, and that only comfort care should be given. This would address uncertainties that prevail, rightly or wrongly.

It would confirm our case law's "unambiguous recognition and acceptance of the right of the patient, who need not be terminal, to refuse a life-saving medical intervention."[2] This right of refusal flows from the right to autonomy or self-determination, which extends to the right to control over one's body.

How clear and explicit is current law? Section 7(1) of the *National Health Act 2003* requires consent for all medical treatment,[3] including, *by implication*, potentially life-shortening treatment. This would mean that a contemporaneous refusal of potentially life-sustaining treatment, constituting an order to withhold or withdraw such treatment, would be

[2] SALC Report, p 43.

[3] Section 7(1) of the *National Health Act, 61 of 2003* says that no health service may be provided without a person's consent, thus creating a general legal prohibition against treatment without consent.

legal. This interpretation is strengthened by Section 7 (1)(e) of the Act which states that refusal of a service that might result in death, but where the service was refused "expressly, impliedly or by conduct", was permissible.

This significant statutory provision for refusal of potentially life-sustaining treatment (which is also an indirect legalisation of a living will – see Section 4.3.1, below) is tucked away in general provisions about informed consent being required for any treatment. This is not good enough. *End-of-life decision-making legislation should remove any residual uncertainty* by clearly stating that it is lawful to refuse potentially life-sustaining treatment, provided certain conditions are satisfied; that the patient does not need to be terminal; that the refusal does not need to be in writing; that medical practitioners are obliged to respect patients' competent preferences in this regard; and that, should they do so in terms of the standard of care for medical practice, they would be immune from criminal or civil prosecution.

Such legislation should also make it clear that there is *no legally relevant difference between the withholding and withdrawal of potentially life-sustaining treatment.*[4] This is necessary given the fairly widespread belief that since withdrawal of potentially life-sustaining treatment is a commission (of killing) and withholding such treatment is an omission (of allowing to die), the latter is ethically acceptable but the former not. This belief is unsustainable. In both cases, the underlying condition of the patient causes death, but withdrawal first allows acute treatment, which is then withdrawn if it proves to be unnecessary or futile. Importantly, both withholding and withdrawal are actions for which people are responsible and can be held accountable, and that – rather than the mere activity or passivity of the action – counts ethically or matters

[4] *Clarke v Hurst NO and others* 1992 4 SA 630 (D), at 633 G-H, held that in determining legal liability for terminating a patient's life, there was no justification for drawing a distinction between the omission to institute life-sustaining treatment and the discontinuation thereof. See SALC Report, pp 203-204. Also see Melodie Slabbert: *op. cit.*, p 143.

morally. References to withdrawal, followed by a natural death, as "killing" are totally inappropriate.

Moreover, *artificial nutrition and hydration* should be recognised as *medical treatment* that can be withheld or withdrawn. The mere thought that someone may die of hunger or thirst, even though the patient does not suffer and the underlying medical condition makes death imminent, some people find, quite understandably, upsetting because of the symbolic meaning of food and water. The SALC Report only refers to "life-sustaining medical treatment"[5] in its draft bill, which includes artificial nutrition and hydration, but finds it unnecessary to mention these explicitly. Of course, the dying process, with or without artificial nutrition and hydration, should be accompanied by terminal pain management and appropriate comfort care generally.

Second, statutory law should recognise the right of competent persons to choose that potentially life-sustaining treatment be withheld or withdrawn at some future time when they might no longer be competent to do so. Such *advance directives* will be dealt with separately (see Section 4, below).

Third, the legal position of *mature or competent minors* refusing potentially life-sustaining treatment should be clarified in statutory law. The SALC Report recognises that chronological age alone may not be a reliable indicator of competence in respect of end-of-life decision-making. In its draft legislation, the SALC recommends that persons above the age of 18 and of sound mind be given legal authority to refuse potentially life-sustaining treatment, whereas persons above 14 years of age and of sound mind would need to be assisted by their parents or guardians.[6]

Subsequently, the *Children's Act 2005* has recognised the autonomy and independent decision-making ability of children of 12 years and

[5] SALC Report, pp 206, 210.
[6] *Idem*, pp 226-227.

older who may now consent to their own medical treatment, including surgery.[7]

The SALC's draft bill is a good place to find guidance on how to formulate such a statutory legal provision for *competent* persons to refuse potentially life-sustaining treatment contemporaneously.[8]

Explicit statutory recognition of the moral right of competent persons to refuse potentially life-sustaining treatment by means of either contemporaneous or advance-directive instructions (see Section 4, below) would amount to the *recognition of a legal right to a natural death*. (Contemporaneous instructions would be by the patient or the patient's substitute decision-maker, and advance-directive instructions would be by means of a living will or power of attorney for healthcare.) Such a right to die could be recognised in a local equivalent of state laws in the United States that recognise a right to a natural death.[9]

Such a statutory provision would confirm the position of the Health Professions Council of South Africa (HPCSA), which states that "the health care professional may alleviate the suffering of a terminally-ill patient by withholding treatment, i.e. allowing the natural process of death to follow its course".[10]

3.3.2 Incompetent Persons without Advance Directives

Incompetent persons lack the capacity to make rational end-of-life decisions and are therefore unable directly to demand that their rights – including their right to dignity – be respected. The Constitution recognises the *inherent right to dignity of every person and to have their dignity respected and protected*.[11] Dignity in the context of withholding or

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[7] *Children's Act, 38 of 2005*, Section 129.
[8] SALC Report's draft bill, section 3(1)-(4), pp 226-227.
[9] *North Carolina General Statutes*, Article 23 §90-321, Right to a Natural Death. http://www.ncga.state.nc.us/EnactedLegislation/Statutes/HTML/ByArticle/Chapter_90/Article_23.html
[10] HPCSA: *op. cit.*, p 1.
[11] *Constitution of the Republic of South Africa Act, 108 of 1996*, section 10. For a brief analysis of balancing the constitutional right to dignity as well as other constitutional rights, on the one hand, with the constitutional right to life, on the other, in respect of as-

withdrawing potentially life-sustaining treatment invokes *quality-of-life considerations*. Treatment that keeps alive the bodily functions of an *incompetent* person, without benefiting the pursuit of a meaningful or worthwhile life, would diminish a person's dignity.

3.3.2.1 Substitute Decision-Making for Incompetent Persons without Advance Directives

How, then, could decisions about withholding or withdrawing potentially life-sustaining treatment be made on behalf of incompetent persons? There are two possibilities.

First, such decisions on behalf of incompetent persons could be made *under the direction of an advance directive which they made while still competent*. (Advance directives are discussed separately in Section 4, below.)

Second, *substitute decision-makers may make contemporaneous decisions on behalf of incompetent persons in the absence of an advance directive*. In this way, a substitute decision-maker exercises the right to dignity of an incompetent person. If an incompetent person did not appoint a substitute decision-maker while still competent, specific individuals may acquire the status of substitute decision-maker in virtue of their *relationship* with the incompetent patient.

What exactly does the law say about substitute decision-making that may potentially shorten life? (Here the focus is on substitute decision-making in the absence of an advance directive. Section 4, below, addresses advance directives, one type of which involves substitute healthcare decision-making on behalf of an incompetent person.)

Section 7(1)(b) the *National Health Act 2003* provides for a competent person, "mandated or authorised" by another person [an "advance directive" – the Act does not use this term], to make healthcare decisions on their behalf, *or, in the absence of such an mandate, for family mem-*

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sisted dying (assisted suicide and voluntary euthanasia), see Section 5.3 of this Position Paper.

bers or others to act as substitute decision-makers on their behalf.[12] (The terms 'substitute', 'surrogate' or 'proxy decision-maker' are not used in the Act.)

The problem, however, is that this barebones provision for substitute decision-making on behalf of a patient forms part of general statutory legal provisions about the requirement of *informed consent* for healthcare decisions. Quite understandably, medical practitioners may feel uncertain, or fear litigation, if they were to withhold or withdraw potentially life-sustaining treatment from a patient when they are directed to do so by a substitute decision-maker. They may fear that a decision that would hasten death may be imprudent, may be made by a compromised substitute, or the like. They may be uncertain about the powers of the substitute, or about formalities that might be required. Or they may regard the treatment demanded by the substitute as futile and thus inappropriate. If there is more than one substitute (say, two children of the patient) and they disagree, whose decision should prevail?

Ideally, a substitute should take the place of the patient in all respects, and their decisions should be respected as if they were the patient's own, even if they are potentially life-shortening. Medical practitioners should not have any residual fear that the substitute's decision is not "really" that of the patient, provided, of course, that the decision meets the standard of care for medical practice. If a competent person can give an advance-direction instruction declining potentially life-sustaining treatment in possible future but specified circumstances in which they might find themselves, then that person's legitimate substitute should be empowered to make that very same kind of decision. The substitute's decision should meet the appropriate standard for substitute decision-making in the circumstances, namely the subjective, substitut-

[12] These provisions of the *National Health Act, 61 of 2003* are set out more fully in Section 4.3 of this Position Paper, where surrogate decision-making is discussed in the context of advance directives.

ed-judgment, or best-interest standard (see definitions in Section 3.1, above).

Given, however, that the substitute's decisions should conform to the appropriate standard of care for medical practice, it follows that *medical practitioners should not be obliged to follow the instructions of substitute decision-makers if the goal of the treatment is unattainable or futile, and thus inappropriate*. Typically, such cases involve demands by the substitute that "everything should be done" regardless of the futility of the treatment and the cost involved. But "(t)here are many kinds of treatment that a patient or her substitute decision-maker might seek that a healthcare provider might wish, or feel compelled, to deny because he believes that there are *insufficient healthcare resources* to meet the demand, it is not in the *patient's best interests*, or it does not meet the *standard of care* for medical practice" (emphasis added).[13]

Statutory legal provision should therefore be made for medical practitioners to decide *unilaterally* to withhold or withdraw potentially life-sustaining treatment, thus overriding a substitute decision-maker. This would preclude scenarios such as Case Study 1 (the ICU case, see Section 3.2.2, above), but it would indeed contradict the SALC Report's draft bill which states that a medical practitioner shall not act in a manner that "would be contrary to the wishes of the interested family members of the patient, unless authorised by the court to do so"[14]. The SALC's position *would open the door for the family to insist on futile and thus inappropriate treatment*, as is the case in the United States. Even if the family could afford to pay, such inappropriate treatment might exclude others from beneficial (non-futile) treatment, for example, an ICU bed. Even though consensus with the family about the withdrawal of potentially life-sustaining treatment is the ideal, if this cannot

[13] Udo Schüklenk *et al*: *op. cit.*, at p 66.
[14] Draft bill in the SALC Report, section 8(1)-(4), p 235-236.

be achieved in some instances, the courts should not be the routine recourse to override inappropriate surrogate preferences.

Of course, this might be viewed as unjustified paternalism. Deciding between respecting and overriding a substitute decision-maker's autonomy requires ethical justification. A key ethical issue would be to determine whether there are any interests at stake justifying a charge of paternalism. For example, an irreversibly non-responsive person may no longer have any direct interests for the decision-maker to consider, which would make a charge of paternalism menaningless. Importantly, with a proper advance directive in place, questions about paternalism would not arise (see Section 4, below).

Particularly in respect of *seriously defective newly born infants*, opinions differ about choosing between withholding and withdrawing life-sustaining treatment.[15] Some prefer withholding treatment because it is less of an emotional burden and is passive rather than active; others prefer withdrawal because it offers a chance to assess the patient's prognosis and chances of successful treatment. Withdrawal also makes it less likely that treatment will be inappropriately withheld when a good outcome is possible. In this regard, The Royal College of Physicians and Child Health (RCPCH) identified five situations where it may be ethical to withhold or withdraw potentially life-sustaining treatment from infants or children – brain death; PVS; "no chance" situations; "no purpose" situations; and "unbearable" situations. These may assist with law reform to achieve greater clarity about medical practices that should be recognised as both ethically and legally permissible.

In essence, decision-making on behalf of incompetent persons requires, first, respecting advance directives (which includes the appointment of a substitute – see Section 4, below) and, second, substitute decision-making in the absence of an advance directive, each with its

[15] Sharon Kling and Mariana Kruger: Chapter 13, Paediatric Ethics, in Keymanthri Moodley (editor): *Medical Ethics, Law and Human Rights: A South African Perspective*. Pretoria: Van Schaik Publishers, 2011, pp 183-202, at pp. 196-199.

boundaries of appropriateness. An end-of-life decision-making bill, incorporating some of the key elements of the SALC Report's draft bill, should provide greater clarity in respect of deciding for others who are incapable of making their own decisions.[16]

3.3.2.2 Forms of Incompetence

There are different forms of incompetence, all of which render one totally and irreversibly incapable of decision-making. In respect of all of these, potentially life-sustaining treatment would be inappropriate because it would be unnecessary and futile. To eliminate uncertainty and provide protection, the law should refer explicitly to persons who are incompetent in the following ways.

Brain Death

First, a patient may be *clinically dead*.[17] The criterion for death in South Africa is brain death in the sense of whole-brain death, that is, the cessation of the functioning of both the cortex (that makes consciousness possible) as well as the brain stem (that enables respiration and circulation). There is no cogent ethical reason for keeping brain-dead people alive through artificial means by, for example, ventilator support.

For transplant purposes, and with the necessary informed consent, keeping a brain-dead person alive for organ harvesting would be ethically justified in terms of both respect for autonomous choices and benefiting others.

Permanent Vegetative State (PVS)

Second, a patient may be *in a permanent vegetative state (PVS)*. The regions of the brain supporting consciousness are totally and irreversibly

[16] See the draft bill in the SALC report, pp 235-6 (refusal and cessation of potentially life-sustaining treatment in the absence of an advance directive) and pp 233-235 (advance directives regarding refusal or cessation of such treatment). For the latter, see Section 4 of this Position Paper.
[17] SALC Report, pp 29-36.

non-functional, but the brain stem still enables spontaneous respiration and circulation.

Case Study 2: The *Clarke*[18] Case

The patient, Dr Clarke, a general practitioner, was left brain-damaged following cardiac arrest. He was resuscitated, but due to prolonged cerebral anoxia he suffered serious and irreversible brain damage, became deeply comatose and went into a PVS. After three years, his wife asked the court to appoint her curatrix with the power to withhold further treatment and to discontinue nasogastric feeds. Although Dr Clarke had signed a living will, the court did not rule on the legal status of a living will, but held that discontinuing medical treatment would not be unlawful. Mrs Clarke was appointed curatrix, Dr Clarke was discharged from hospital and died at home on 14 August 1992.

The court's reasoning is instructive. The court held that "(a) duty not to discontinue life-sustaining procedures could not arise if the procedures instituted have proved to be unsuccessful. *The mere maintenance of certain biological functions such as heartbeat, respiration, digestion and blood circulation, without the functioning of the* [higher, consciousness-enabling] *brain, cannot be equated with life*. It would therefore *not be unlawful to discontinue the artificial maintenance of that level of life* (emphasis added)"[19].

The court further held that, in cases such as these, it would not be contrary to public policy if a court would make an evaluation of the *quality of life* of the patient in order to determine whether life-sustaining measures should be discontinued.[20] Wrongfulness should be judged according to the *boni mores* of the community, and that *boni mores* is, in turn, dependent on the quality of life of the patient, that is, the facts of the particular case. In the case of Dr Clarke, a PVS patient, the court held that it would not be wrong for Dr Clarke's substitute decision-maker (his wife) to authorise the cessation of the patient's artificial feeding, even though this would hasten death.

[18] *Clarke v Hurst NO and others* 1992 4 SA 630 (D). See èage 61.
[19] SALC Report, p. 204.
[20] See footnote 35.

See The Clarke Case, Case Study 2, which is probably the best authority regarding the legal position in South Africa in respect of life-sustaining duties towards PVS patients.

Statutory law should go further and confirm the *Clarke* case regarding continued life of PVS patients.

Should a PVS patient have an advance directive, such as a living will, it should be respected and protected by law. (See Chapter 4, below.)

Lack of Higher Brain Function

Third, persons may have *large-scale, irreversible lack of higher brain (cortical) function* and therefore severe cognitive impairment, enabling only rudimentary awareness of their surroundings, including sensations of pain and discomfort, but with no ability to communicate or respond meaningfully to their environment. Such severely diminished mental life may have many different causes, such as head injury, dementing disease, or deprivation of oxygen. It *may be difficult to determine a patient's exact state of awareness by means of brain and behavioural criteria*. Such patients should be distinguished from patients with locked-in syndrome[21] who can experience and understand, but are unable to move or communicate, and are clearly competent.

Prof Melodie Slabbert (Professor of Jurisprudence, School of Law, University of South Africa), notes that "(t)he result of the judgment in this [the *Clarke*] case is generally regarded by jurists in South Africa as recognition, within the narrow factual parameters of the case, of (lawful) passive euthanasia [withholding and withdrawal of potentially life-sustaining treatment]".[22] Statutory law should reach beyond the confines

[21] "Locked-in syndrome is a condition in which a patient is aware and awake but cannot move or communicate verbally due to complete paralysis of nearly all voluntary muscles in the body except for the eyes. Total locked-in syndrome is a version of locked-in syndrome where the eyes are paralyzed as well." From http://en.wikipedia.org/wiki/Locked-in_syndrome (26 March 2012).

[22] Melodie Slabbert: *op. cit.*, p 144.

of the Clarke case and, more generally and explicitly, allow the withholding or withdrawal of potentially life-sustaining treatment from persons who are *neither clinically dead nor in a PVS, but have irreversible, extremely diminished consciousness, or no consciousness at all* (see, for example, the ICU case, Case Study 1, in Section 3.2.2, above). This would be an extension of the principles of the *Clarke* case – for example, that life should not be maintained at all cost irrespective of its *quality* – from a *specific* PVS patient (Dr Clarke) to PVS patients *in general* and to *non*-PVS patients with some rudimentary consciousness, or no consciousness.

Their treatment should only be in pursuit of an appropriate goal, given their diagnosis and prognosis. Moreover, it should be legally permissible to withhold aggressive antibiotic treatment of a life-threatening infection that would only serve the purpose of delaying a natural death (see Case Study 1, in Section 3.2.2, above.) This should in no way detract from the need to provide appropriate and adequate comfort care (see Section 2.2, above).

This category of incompetent patient allows for many different variables and clinical diagnoses and prognoses. Of course, there will always be stories of miraculous recoveries. As in all human affairs, absolute certainty cannot be guaranteed. Clinicians should apply their minds and make responsible, standard-of-care judgments in the circumstances.

Again, advance directive should be written into statutory law, and should be respected by family members and other substitute decision-makers as well as clinicians. (See Section 4, below.)

Depression

Fourth, the impact of *depression* in its various forms and degrees on a patient's competence to make end-of-life decisions needs broad statutory guidelines based on responsible, standard medical practice. Depression may be a natural accompaniment of finding oneself in a state of terminal decline without necessarily rendering one incompetent. Some

forms of depression would indeed render one incompetent, but may be successfully treated, thus opening the scope for competent decision-making. It is acute chronic depression that fails to respond to treatment which poses the most difficult challenges to end-of-life decision-making. In short, it may be desirable to formulate broad legal guidelines about the relevance of depression for the determination of competence.

Severely Defective Newly Born Infants

Fifth, the legal position regarding the withholding or withdrawal of potentially life-sustaining treatment from *severely defective newly born infants* should be clarified. The same considerations apply as in the case of incompetent adults, although the fact that newly born infants have never been competent and therefore have never had a chance to live a full human life, may, in some cases, incline one towards instituting life-sustaining treatment, guided by the best-interest standard, to determine whether they have any chance of a worthwhile life, and then withdrawing life support if this proves futile.[23] However, accurate diagnosis of extreme deficiency would make this unnecessary and undesirable.

Aspects of Decision-Making for Incompetent Persons

There should also be statutory legal clarity about *how* decision-making should proceed in respect of incompetent patients without advance directives, with *consensus* among surrogate decision-makers and attending medical practitioners being the ideal. In the absence of such consensus, attending medical practitioners should receive immunity from prosecution for *unilaterally* withholding or withdrawing life-sustaining treatment provided that (1) the healthcare requested by the substitute decision-maker runs counter to responsible standard-of-care medical practice and is therefore futile and inappropriate in the circumstances, and that (2) adequate comfort care is not compromised. Moreo-

[23] See footnote 31 and accompanying discussion. Also see Melodie Slabbert: *op. cit.*, p 145.

ver, the law should recognise that administering *artificial nutrition and hydration* is a form of medical care that may be withheld or withdrawn, accompanied by appropriate comfort care.

Any law aimed at providing greater clarity, may need to mention specific options regarding the withholding and withdrawal of potentially life-sustaining treatment. Apart from artificial nutrition and hydration, there are intravenous (IV) fluids, nasogastric (NG) tubes, DNR orders and the like.

For DNR-orders, for example, the standard of care for medical practice is to perform cardio-pulmonary resuscitation (CPR) in the absence of a valid medical practitioner's order to withhold it.

Routine recourse to the courts to decide on appropriate treatment or to settle disagreements among substitute decision-makers and medical practitioners about appropriate care should be avoided.[24]

Given irreversible, total or almost total lack of consciousness, decisions about the withholding or withdrawal of potentially life-sustaining treatment should be left to substitute decision-makers and attending medical practitioners.

Finally, the SALC Report clearly expresses the need for legal reform in respect of withholding or withdrawing potentially life-sustaining treatment from *incompetent patients without advance directives*: "Legislative confirmation and clarification of the position where there is no advance directive… are necessary."[25] This was said 14 years ago. It is still true today.

[24] See the draft bill, section 8(2), in the SALC Report, p 235.
[25] SALC Report, p 209.

4

ADVANCE DIRECTIVES

Advance directives involve an end-of-life decision-making practice that recognises the *moral right of individuals to future control over their bodies* in the eventuality that they may become incompetent to make their own end-of-life *or* routine decisions, as well as the corresponding moral obligation of caregivers, family and the state to respect that right. The law should be clear about the legal status of this right and obligation.

4.1 Terminology

Key terms for a discussion of the ethics and law of advance directives are the following:

- An 'advance directive' is an arrangement made by competent persons regarding their healthcare treatment in the eventuality that they might become incompetent to make their own healthcare decisions. Such directives may be about the circumstances surrounding possible future treatment, the kinds of treatment, or by whom decisions should be made. *There are two main classes of advance directives*:
  - A '*living will*' is an *instruction directive* by means of which a competent person instructs others to *withhold or withdraw potentially life-sustaining treatment should they become incompetent to refuse such treatment themselves*. For example, a person may sign a document instructing others to withhold or withdraw all

medication such as antibiotics and including artificial nutrition and hydration, should they fall into a permanent vegetative state (PVS) or become irreversibly non-responsive.

- A '*durable power of attorney for healthcare*' is a *substitute directive* by means of which a competent person *appoints or mandates a specific person as their substitute (proxy, surrogate) healthcare decision-maker should they become incompetent to make their own healthcare decisions*. Such a power of attorney may confer *general* decision-making powers on the substitute, for example, to make *all* healthcare decisions – including decisions about refusal (withholding or withdrawal) of potentially life-sustaining treatment – on behalf of the patient. In addition, the substitute decision-maker may also be given *specific* instructions, for example to refuse potentially life-sustaining treatment in specific circumstances, such as severe and irreversible lack of brain function. This kind of power of attorney is *durable* because once the patient becomes incompetent it remains in effect.

4.2 Ethical Considerations

Competent persons may foresee the possibility of becoming incompetent when in the terminal phase of the dying process, and may wish to control their future healthcare decision-making while they are still competent. Advance directives are designed to give competent persons the choice to express their preferences and give instructions about such possible future situations.

The ethics of advance directives is merely an extended application of the ethical values of autonomy, well-being, and respect for human dignity that find expression in contemporaneous end-of-life decision-making by competent persons (see Section 3, above).

An advance directive extends a person's competent preferences beyond the possible future loss of competence, when they would be unable

to express contemporaneous treatment preferences. So, if one accepts the ethics of contemporaneous end-of-life decision-making regarding the withholding and withdrawal of potentially life-sustaining treatment, then one should also accept the ethics of decision-making by means of advance directives.

The refusal by people to respect or honour a patient's advance directives is a significant ethical issue. There are various explanations for this tendency, such as fear of litigation, failure to come to terms with a relative's impending death, ignorance of the dying process, having different belief systems and the like.

4.3 A Case for Legal Clarity

Dying is a part of life, but we tend to avoid talking about it until it happens to a close relative or friend, or to ourselves. Clear affirmation, in statutory law, of the legal status of advance directives would assist in focusing people's minds on making timeous decisions about possible future scenarios in which they would not want to find themselves without any say in the matter of their appropriate treatment.

Globally, advance directives are recognised in the laws of many countries.[1] For example, a federal law in the United States, the *Patient Self-Determination Act (PSDA)*, passed by the US Congress in 1990, has the purpose "to inform patients about their rights regarding decisions towards their own medical care, and ensure that these rights are communicated by the health care provider. Specifically, the rights ensured are those of the patient to dictate their future care (by means such as a living will or power of attorney), should they become incapacitated"[2]. According to the *PSDA*, healthcare institutions are required to inform adult pa-

[1] *Idem*, pp 158-181.

[2] http://en.wikipedia.org/wiki/Patient_Self-Determination_Act. The PSDA seeks to promote the rights (1) to facilitate one's own health care decisions, (2) to accept or refuse medical treatment, and (3) to make an advance health care directive.

tients upon admission to a healthcare facility about their rights to facilitate their own healthcare decisions, to accept or refuse medical treatment and to make an advance healthcare directive.

In South Africa, advance directives (specifically a living will) are recognised by the HPCSA.[3] The current legal position is set out in the *National Health Act 2003*.[4] *The provisions in our law regarding advance directives, although a step in the right direction, are inadequate.* It would be useful if our law accepts the widely-accepted terms 'living will' and 'durable power of attorney for healthcare' (or simply 'power of attorney'), but the uncertainty about advance directives goes deeper than mere terminology.[5]

4.3.1 Living Will

First, in respect of a living will, in section 7(1)(e) the Act states that "a health service" may not be provided to a person without informed consent unless "the user has not expressly, impliedly or by conduct refused that service". *This implies indirectly that a living will which refuses potentially life-sustaining treatment must be acted upon by a medical practitioner*.[6] The Act is correct to conceptualise a living will as having a narrow focus, namely, a *refusal* of potentially *life-sustaining* treatment.

However, it should not be necessary to *infer* a living will from one phrase in the section of an act that deals with informed consent in general. A living will should be explicitly recognised and issues surrounding it should be addressed – such as its purpose and scope; format and minimum formalities; whether it may in any circumstances be overrid-

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[3] HPCSA: *op. cit.*, p 51.
[4] *National Health Act, 61 of 2003*.
[5] For a more detailed discussion of choices that face advance-directives legislation, see Willem A Landman and Lesley D Henley, Legalising Advance Directives in South Africa. *South African Medical Journal*, Volume 90, Number 8, pp 785-787, August 2000.
[6] Keymanthri Moodley, Chapter 17, Ethics at the End of Life, in Keymanthri Moodley (editor): *Medical Ethics, Law and Human Rights: A South African Perspective*. Pretoria: Van Schaik Publishers, 2011, pp 267-280, at p 274.

den by family or medical practitioners; and whether someone acting on it is immune from criminal and civil liability.

The SALC Report[7] refers to Prof SA Strauss who states that a living-will refusal of *any* treatment would oblige medical practitioners to give effect to such explicit statements, and that they could even expose themselves to liability should they disregard the patient's wishes. These interpretations should be unambiguously affirmed in legislation that clarifies the legal status of a living will.

4.3.2 Durable Power of Attorney for Healthcare

Second, the Act, in sections 7(1) (a) and (b), allows for the appointment of a substitute healthcare decision-maker. In section 7(1)(e), the Act states that "a health service" may not be provided to a person without informed consent unless "mandated by the user in writing to grant consent on his or her behalf." Regarding such a mandate, in section 7(1)(a), the Act provides for any person to mandate another person in writing to grant consent on their behalf should they become unable to do so, and, in section 7(1)(b), the Act provides for a priority list of family members and others who may grant such consent in the absence of a specific mandate.

As with a living will, there is a need to clarify the legal status of a durable power of attorney for healthcare. Would the "health service" to which the Act refers include health services which could, should they be withheld or withdrawn, potentially hasten death? Are there any circumstances in which a substitute's decision may be overridden by family or medical practitioners, provided it complies with other laws? What if the attending medical practitioner has good reason to believe that the treatment demanded by the substitute is futile and therefore inappropriate? What if the application of the Act means that there are two substitute decision-makers – for example, two children – and they disagree about the

[7] SALC Report, p 182.

treatment their parent should receive? And would a substitute and medical practitioner be immune from civil and criminal liability, provided decisions are responsible, in accordance with the standard of care for medical practice and do not constitute medical malpractice?

Following proper statutory recognition, the practical challenges of advance directives would need to be addressed. For example, people would need to be educated about the purpose and benefits of advance directives. There would need to be extensive communication on how to complete advance directives, where to lodge them so that they are available when needed, and on their availability in acute-care settings as well as in long-term care facilities.

Survey of medical doctors' attitudes: Usefulness of advance directives

In the 2011 scoping survey of South African medical practitioners, a vast majority of 75% agreed that advance directives (living wills and powers of attorney for healthcare) assist to clarify patients' wishes regarding treatment at the end of life or when incompetent, while only 12% disagreed.[8] One could expect this positive response to rise, should legislation be passed to clarify outstanding issues, accompanied by a public education campaign.

The SALC Report unequivocally supported statutory recognition of advance directives, provided that compliance with the wishes set out in the document would not be unlawful.[9] It did not favour rigid legal requirements.

The Report underlined the need to provide legal protection for medical practitioners, and others acting under their direction, against civil and criminal liability if potentially life-sustaining treatment was suspended. It also supported a conscience clause for medical practitioners wishing to opt out. In addition, it held that a living will should only be

[8] See Addendum, Figure 11.
[9] *Idem*, pp 190-193.

recognised as valid and legally enforceable in so far as it requests the withholding or withdrawal of life support, not the active ending of life (see Section 5, below, for assisted suicide and voluntary euthanasia).

5

ASSISTED DYING – ASSISTED SUICIDE AND VOLUNTARY EUTHANASIA

Assisted dying (assisted suicide and voluntary euthanasia) is an end-of-life decision-making practice that recognises the *moral right to assisted dying of individuals in the terminal phase of dying*, as well as the corresponding moral obligation of caregivers, family and the state to respect that right.

Whereas the preceding three practices (terminal pain management; withholding and withdrawal of potentially life-sustaining treatment; and advance directives) simply require greater legal clarity than is currently the case, assisted dying would require *substantial legal reform – decriminalisation* – since it is unlawful in both its forms. The key question is whether legalising assisted dying would be consistent with – or perhaps even required by – the bill of rights in the Constitution, particularly the right to life.

5.1 Terminology

Key terms for a discussion of the ethics and law of assisted dying are the following:

- '*Assisted dying*', in its *wider* sense, refers to all end-of-life interventions in the dying process – (i) terminal pain management and comfort care; (ii) withholding and withdrawal of potentially life-sustaining treatment; (iii) respecting advance directives; and (iv) as-

sisted suicide and voluntary euthanasia. In its *narrower* sense, 'assisted dying' refers only to the last category, namely *assisted suicide* and *voluntary euthanasia*. The significance of using 'assisted dying' as an umbrella term for these two acts is that they, although distinguishable, are sufficiently similar acts from both ethical and legal perspectives to justify such a joint classification. Whereas the SALC Report and draft bill use the umbrella term 'euthanasia' for these two acts, this Position Paper prefers 'assisted dying' or 'assistance with dying', that is, in the narrower sense.[1] (Analogously, we decriminalised 'termination of pregnancy', not 'abortion', in precisely defined conditions.[2])

- '*Assisted suicide*' (or '*doctor-assisted suicide*' or '*physician-assisted suicide*') occurs when a medical practitioner or other person intentionally provides the *means* for a competent person to take their own life, in which case the *patient's act* is the *proximate cause* of death in the causal chain of acts, events and conditions that result in the patient's death. For example, a medical practitioner, in response to a request by a competent patient, writes a prescription for a lethal drug whereupon the patient ingests it and dies. Or a family member gathers a sufficient dosage of lethal substances, enabling the patient to ingest them and die.
- '*Euthanasia*' comes from the classical Greek words '*eu*' (good) and '*thanatos*' (death) and thus literally means 'a good death', 'a gentle death' or 'dying well'. More technically, 'euthanasia' means intentionally causing the death of a person, for that person's own sake, where a positive *act of another person*, and not the natural process of dying (as with withholding or withdrawal of potentially life-sustaining treatment), is the *proximate cause* of death.

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[1] SALC Report p 80 (at 4.109). It regards both assisted suicide and voluntary active euthanasia as versions of "active euthanasia" (or "assisted dying", as in this Position Paper) that should be dealt with accordingly. The 2011 scoping survey confirms that medical practitioners agree about this similarity (Addendum, Figures 3 and 4).

[2] See Footnote 3 on the abolition of capital punishment on constitutional grounds.

- From the *perspective of the person who causes another's death*, 'euthanasia' has two meanings:
  - '*Passive euthanasia*' is a term used for contributing to the death of a person by the intentional *withholding or withdrawal of potentially life-sustaining treatment* from a competent or incompetent person so that a *natural death* can set in, where death is reasonably believed to be in that person's interest, or continued life is reasonably believed to be no longer worthwhile (see Section 3, above). An *inaction* or *omission* ("not doing" or refraining from doing something), like an *act* or *commission* ("doing" something), is a subclass of *actions*, both involving responsibility for choices and decisions. Apart from terminological clarification, this Position Paper, however, does not use the term 'passive euthanasia', but instead uses the terms 'withholding' or 'withdrawal' of potentially life-sustaining treatment.
  - '*Active euthanasia*' means intentionally causing the death of a competent or incompetent person by means of an *act* or *commission* ("doing" something) that is the proximate cause of death, where death is reasonably believed to be in that person's interest, or continued life is believed to be no longer worthwhile. Again, an *act*, like an omission, is a species of *actions* involving responsibility for choice, for example administering a lethal injection. Apart from terminological clarification, this Position Paper does not use the term 'active euthanasia', but prefers the terms 'assisted dying' or 'assistance with dying'.
- From the *perspective of the person who dies*, 'euthanasia' has three meanings:
  - '*Voluntary euthanasia*' (in the sense of 'voluntary *active* euthanasia', also called '*mercy killing*') means that a competent person freely (without duress or coercion) requests a medical practitioner or other person for assistance with dying on account of suffer-

ing in the end-stage of a terminal disease, or unbearable and intractable suffering, whereupon the medical practitioner or other person obliges with an intentional act that is the proximate cause of death.

- '*Non-voluntary euthanasia*' refers to cases where a competent patient's wishes cannot be known – either because they are no longer competent (for example, a person in a PVS without an advance directive), or have never been competent (for example, a severely defective newly born infant) – and their death is brought about by the intentional act of a medical practitioner or other person, where death is reasonably believed to be in that person's interest, or continued life is reasonably believed to be no longer worthwhile.
- '*Involuntary euthanasia*' refers to cases where a competent person is intentionally killed for their own good, but against their wishes. For example, a bystander kills a driver trapped in his burning truck for compassionate reasons, or for his own good, but against the wishes of the driver, because there is no prospect of rescuing him from a certain, cruel death.

5.2 Ethical Considerations

Crucially, both the ethics and law of assisted dying (assisted suicide and voluntary euthanasia) deal with *free or voluntary choices by competent persons to end their lives. No-one is forced, coerced or unduly influenced to make that decision.*

From the point of view of the dying person, at issue here is only a *voluntary* assisted dying, with a person freely requesting such assistance. Still, ethics and the law would need to address *non-voluntary* assisted dying too (where persons irreversibly lack, or have never had, the capacity to decide for themselves), for example, severely defective newly

born infants. Although this Position Paper does make some observations about non-voluntary euthanasia, it does not deal with it systematically. Proper recognition of advance directives as well as substitute decision-making would reduce, but not eliminate, the need for non-voluntary euthanasia.

Involuntary euthanasia is rejected in a medical setting, and only referred to in a discussion of the Nazi "euthanasia" projects.

In short, *any talk of unilaterally "deciding for (competent) others" that they should die, is totally out of place in this discussion*.

Assisted dying is a highly controversial and emotive topic. Ethical beliefs about these practices are steeped in religion, and thus interpretations or understandings of the doctrine of the sanctity (special moral value) of human life. The mere fact that views are personal and strongly held, whether inspired by religion or not, does not justify the suppression of responsible public debate about those views. On the contrary, *we have a compelling ethical obligation to address assisted dying in the democratic process, as we did with respect to capital punishment and termination of pregnancy (abortion)*. Our public policy should not be driven by partisan religious beliefs – often resting on mistaken assumptions and projections that religion forbids these practices – but rather by our Constitution.

The bill of rights in the Constitution is an ethical document that sketches the basic values upon which our democracy is to be built and proposes human rights that we should realise progressively. So, *a key question regarding legalising assisted dying would be its constitutionality*. In short, *do we have an ethical obligation to decriminalise assisted dying, given the values and rights in the Constitution?*

But by focusing on the ethics of *legalising* assisted dying (the ethics of legalising a practice), rather than on the ethics of assisted dying *itself* (the ethics of the practice), might we not end up legalising a practice that is regarded as fundamentally unethical, similar to legalising abortion

which the majority of the population probably regarded as unethical at the time? In short, can assisted dying be ethically justified?

This Position Paper is, in the first place, concerned with the ethics of *legalising* end-of-life decision-making, including the ethics of legalising assisted dying. Still, because there are such strongly held and hotly contested ethical views about assisted dying, *a persuasive ethical case for assisted dying would reinforce the ethical need for legalising assisted dying*.

The respective cases for and against assisted dying can each muster at least three key ethical arguments in their support.[3]

5.2.1 Ethical Arguments for Assisted Dying

The argument from autonomy and the argument from suffering make the most powerful ethical case for assisted dying. A third argument contends that assisted dying is ethically speaking the same as withholding and withdrawal of potentially life-sustaining treatment, both of which are widely accepted to be standard-of-care medical practices.

Implicit in these three ethical arguments for assisted dying is the view that *it is not always wrong intentionally to bring about someone's death*, whether by an act or by an omission. Correspondingly, someone's right to life does not entail an obligation to live; or someone may have a right to die, given clearly defined circumstances.

We already accept ethical justifications for other forms of causing death, for example, individual self-defence and in a defensive war. But the three arguments for assisted dying are different because, in the circumstances, those whose life it is, do not regard their own dying as wrong, nor death as bad, but rather as desirable in defined circumstanc-

[3] See Willem A Landman, The Ethics of Physician-Assisted Suicide and Euthanasia. *South African Medical Journal (SAMJ)*, Volume 87, Number 7, July 1997, pp 866-869; Physician-Assisted Suicide and Voluntary Euthanasia: A Response. *South African Medical Journal (SAMJ)*, Volume 88, pp 242-243, 1998; Legalising Assistance with Dying in South Africa. *South African Medical Journal (SAMJ)*, Volume 90, Number 2, pp 113-116, February 2000.

es. This is so because suffering has broken the connection between life and good, so that death becomes a good, or in the patient's best interest (see Section 3.2, above).

5.2.1.1 Personal Autonomy

The *argument from personal autonomy* or *individual self-determination* goes as follows: respect for autonomy is a basic ethical principle which asserts that competent persons have a moral right to make their own choices, including choices about their own continued life in clearly defined circumstances, and to act upon those choices. We have an ethical obligation to respect that right. Consequently, medical practitioners, or specified other people, should have the choice to respect people's autonomous wishes by assisting them with dying, their consciences permitting.

One line of critique against the autonomy argument is that the sanctity (special moral value) of human life outweighs or trumps considerations of autonomy used to justify the taking of human life. But, surely, the sanctity of human life does not reside in biological human life, but in human life that comes up to a certain standard (has a certain quality).[4] Human life characterised by uncontrollable pain due to a terminal disease, for example, fails to meet that standard, judged by the person whose life it is.

A second critique attacks the notion of autonomy, arguing that ethical debate about assisted dying "assumes an ethic of radical individualism" that is based on a "contractual model of care".[5] According to this view, any debate that contemplates the ethical justification of assisting an individual to die, is of necessity anti-community and as such dismissive of the fact of our interconnectedness and interdependence.

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[4] This ethical argument is consistent with the Constitutional Court's suggested in *S v Makwanyane* [1995 2 SACR 1 (CC)] in the context of the death penalty, namely, that the right to life cannot be properly understood without the right to dignity.

[5] Jonathan Victor Larsen: *op. cit.*

This view is surely contradicted by overwhelming anecdotal evidence of cases where requests for assistance with dying are made in a caring, personal setting in which our relationships with, and interdependence on, others are fully recognised and actually constitute the very foundation of a moral obligation to assist with dying (see Section 3.2.1, above). Appeals to community need to define "community" since we are all at once members of several overlapping communities, from immediate family to the global community. If any one of these communities respects the right of an individual to request assistance with dying in defined circumstances, it does not for that reason cease to be a community. And even if someone's request for assistance with dying were to spring from "radical individualism" that is embedded in a contractual rather than caring relationship, that would in no way invalidate the ethical case for respecting personal autonomy.

Moreover, the argument that adequate terminal pain management would remove the need for assisted dying, fails to give due recognition to the personal autonomy of persons in a terminal phase of dying by prescribing to them how they should deal with their suffering induced by pain and distress (see Section 2.2, above).[6]

5.2.1.2 Suffering

Suffering is an emotional response to significant pain or distress. The *argument from suffering* is premised on the value of human well-being. Life, the good that makes all other goods possible, may become a burden or worthless on account of suffering extreme, all-consuming pain, or suffering intractable distress at the loss of control and dignity. Death may become the only deliverance.

Judging another's well-being, or whether life is worth living, or death desirable, is not merely a matter of considering *objective* facts, such as medical information about diagnosis and prognosis. It also re-

[6] See footnote 12 and accompanying discussion.

quires considering the *subjective* values, projects, preferences and experiences of the person whose life and well-being is at issue (see Section 3.2.1, above).

Consequently, if a competent person freely judges that death is the only escape from suffering, then assisting that person to die would not wrong or harm them but be in their interest. On the contrary, refusing help would harm them by frustrating their projects and preferences, and would be crueller and less merciful than assisting them with a gentler, more dignified death.

The counter-argument usually maintains that the suffering caused by pain or distress is controllable by means of comfort care. Again (see Section 2.2, above), to maintain that pain medication, coupled with a conventional dosage of sedative, would keep patients asleep until they die naturally[7], ignores their legitimate preferences not to die in a state of palliative or terminal sedation. And it does not address suffering induced by distress at the loss of dignity.

Another counter-argument contends, from a religious point of view, that God has a purpose with suffering and that we would frustrate his will when we remove suffering by hastening death. Not all religious believers would accept this interpretation of God's will. Moreover, for what sound ethical reason would we wish to relieve others' suffering throughout their lives, but retreat if suffering occurs when death is imminent and relief of suffering may hasten death?

5.2.1.3 Moral Equivalence

There is a strong argument for assistance with dying premised on the *moral equivalence* of *assistance with dying* (assisted suicide and voluntary euthanasia), on the one hand, and the *withholding and withdrawal of life-sustaining treatment*, on the other. If the latter are ethically justi-

[7] See footnote 12 and accompanying discussion.

fied standard-of-care healthcare practices, so should be the former, since there are no relevant moral differences between the two.

The mere fact that one action is an omission or "passive", while the other is an act or "active", does not in itself render the former morally acceptable and the latter morally objectionable.[8] All these practices involve deliberation about the patient's condition, intention, benevolent motive, and consequences – directly for the patient who dies, and indirectly for family, friends, healthcare workers, other interested parties, and state interest. The only difference is the means whereby death is caused: withholding or withdrawing life-sustaining treatment involves an omission of treatment, whereas assisted dying requires an act. This, however, is not a morally relevant difference because we are morally responsible for both acts and omissions.

In short, there is no one set of distinctions or differences that attach only to either acts or omissions.

A counter-argument could be that this moral equivalence thesis is overly intellectual or abstract. The reality of medical practice is that while refusal of life-sustaining treatment has always been – albeit often reluctantly – part of standard-of-care medical practice, this has not been the case with assisted dying. In practice, an ethical borderline has traditionally been observed and there would be a deeply ingrained resistance to crossing it, and consequently medical practitioners would refuse to participate in assistance with dying.

Section 5.2.2.2, below, engages with this counter-argument by focusing on medical practitioners' professional duties. Suffice it to point out here that the same issue arose with termination of pregnancy (abortion). While we should respect medical practitioners' right to refuse to assist with dying, others who wish to follow their conscience and assist with dying should be equally free to do so, subject to clearly defined condi-

[8] James Rachels: Active and Passive Euthanasia. *New England Journal of Medicine*, Volume 202, 1975, pp 78-80.

tions. Simply appealing to tradition or personal conscience does not justify blocking a practice supported by strong ethical arguments.

5.2.2 Ethical Arguments against Assisted Dying

There are three significant ethical arguments against assisted dying: it is wrong to "play God"; the responsibilities of healthcare workers should never include killing people; and "slippery slope" undesirable consequences, including abuse, will follow or are likely to follow.

5.2.2.1 Playing God

The doctrine of the sanctity – or special moral value – of human life means, among others, that *only God should determine the time and manner of our death*. It is therefore wrong to "play God" by shortening our lives, even if suffering is intractable and unbearable.

Clearly, people have different views about the existence of God, and divergent interpretations of coming to know what his will is for us. For some, he is authoritarian and inscrutable, giving us orders and instructions, for example, in the form of a Bible text or some personal revelation. For others, he is a merciful and understanding being who confers upon us autonomy and responsibility to do our best through rational and compassionate decisions in situations of great tragedy and ambivalence.

But even if we accept an authoritarian concept of God, his orders or instructions still need to be *interpreted*. For example, if God prohibits us from usurping his authority by making decisions that alter (hasten) the time of our death, then surely we likewise "play God" when we shorten our lives with bad eating habits, or lengthen our lives with antibiotics or surgery. Which, then, is acceptable in the eyes of God, and which not?

In essence: the "playing God" argument is weak since it is impossible to make a *non-arbitrary distinction* between practices of which God approves and those of which he disapproves. Something is not right because God says so; God says so because it is right. Irrespective of our re-

ligious convictions, we need to use our reason and compassion to come to know what course of action ethical values demand of us.

5.2.2.2 Professional Responsibilities

A second anti-assistance with dying argument contends that *healthcare professionals have responsibilities that are incommensurable with killing or shortening life*, namely, *general* moral obligations as human beings to prevent harm (non-maleficence) and do good (beneficence), and *specific* professional and institutional duties to care, heal, extend life, or preserve life. Assisted dying would undermine these responsibilities and commitments, thus eroding the trust patients have in healthcare professionals to act in their best interests. These practices are forms of killing, and killing is not what healthcare professionals do, or ought to do. And this professional prohibition against killing goes right back to the Hippocratic Oath.

This argument fails to take adequate account of the non-curative healthcare of terminally ill persons whose death is imminent. Life is finite, and all humans will eventually die of natural causes unless some unnatural cause intervenes. Tragically, a natural death, for some, may be infused with intractable or unbearable suffering, and death may be preferable to a life that is no longer worth living. It follows that the ethical responsibilities of healthcare professionals cannot, in all circumstances, be to save life or to heal. Healthcare professionals, or others, who assist with dying, would be morally blameworthy only if death is the enemy in all circumstances, and is therefore to be resisted at all cost. But this would be a denial of the fact that dying is an integral part of life.

In short, there are tragic situations where healthcare professionals' routine goals of restoring health or preserving life are unattainable, and indeed inappropriate, and times when assistance with dying may indeed constitute desirable and appropriate care.

Certainly, those who assist with dying, should this practice be decriminalised, should have the right to opt out of participating in such

practices if these clash with their conscience, as is the case with termination of pregnancy (abortion) in South Africa.

5.2.2.3 Slippery Slope

A significant argument against assistance with dying is that practising it would have *ethically undesirable or unacceptable consequences*, such that it would be better to refrain from it altogether.

Proponents of this argument predict a variety of undesirable consequences. For example, it is claimed that some healthcare professionals would abuse their social standing and power to exert undue influence over vulnerable patients to end their lives, thus embarking upon a slippery slope towards non-voluntary or even involuntary euthanasia. This would undermine the trust people have in healthcare professionals and the medical profession. Others hold that hospice care, pain relief and comfort care would be undermined.

This argument is not about assistance with dying being morally wrong in itself, or intrinsically wrong, but about its possible or probable effects. Presumably, then, if predicted bad consequences fail to materialise, assistance with dying as such would be ethically acceptable.

Any responsible practice of assistance with dying would need to put in place strict guidelines and effective safeguards to prevent undesirable consequences, accompanied by monitoring, reporting and oversight.

Predicted bad consequences remain just that – predictions that are not inevitable, but may turn out to be alarmist and false. Although the slippery-slope argument has intuitive appeal, both its logical and empirical versions[9] are questionable.

First, according to the *logical version*, the justification used for assisted dying would also justify other forms of killing that are clearly wrong. It does, however, not follow, on logical grounds, that the reasons justifying assisted dying – such as respect for autonomy and human dig-

[9] Helga Kuhse, Euthanasia, in Peter Singer (ed.), *A Companion to Ethics*. Oxford: Basil Blackwell, 1991, pp 294-302.

nity and compassion (mercy) – would also justify killings that are neither respectful of autonomy and dignity, nor merciful. People routinely make a clear distinction between ethical and unethical practices, even if they are otherwise closely related, including justified and unjustified forms of killing, for example, in self-defence or war. Moreover, there is no logical reason why medical practitioners, even (improbably) assuming that they might sometimes wish their patients dead for malevolent reasons, would slide down a slippery slope only in respect of one subset of end-of-life decisions, namely assisted dying. It seems perfectly reasonable to assume that what is true of terminal sedation, or the withholding and withdrawal of potentially life-sustaining treatment, is *prima facie* also true of assisted dying. Logically speaking, slippery-slope dangers would be equally existent or non-existent in either case.

Second, the *empirical version* of the slippery-slope argument holds that assistance with dying will, as a *matter of fact*, lead to unjustified forms of killing, such as involuntary euthanasia. If this were in fact true, one would expect there to be evidence of all kinds of other slippery slopes in end-of-life decision-making, for example, that the standard-of-care medical practice of refusing life-sustaining treatment would also put society on a slippery slope towards assisted dying.

On the contrary, available evidence does not bear this out. A comparative study of limitation (rationing) of life support in intensive care units (ICUs) in the United Kingdom and South Africa, shows no significant differences – across the developed/developing world "divide". [10] Where physician-assisted suicide is legal, for example in the states of Oregon and Washington in the United States, there is no credible evidence for a slippery slope to voluntary active euthanasia.[11] More gener-

[10] JS Turner, WL Michell, CJ Morgan *et al*, Limitation of Life Support: Frequency and Practice in a London and a Cape Town Intensive Care Unit. *Intensive Care Medicine*, Volume 22, 1996, pp 1020-1025.

[11] See http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx for the official annual reports on physician-assisted suicide practised in the state of Oregon following the enactment of the *Death with*

ally, proponents of the slippery-slope argument need to produce credible evidence that the withholding or withdrawal of life-sustaining treatment would lead to abuse of vulnerable patients.[12] Lack of such evidence is not surprising, since decision-making in this context involves loving family members and caring, professional healthcare professionals.

Nevertheless, risk inherent to assisted dying should be closely monitored, for example to ensure proper informed consent. Interestingly, a significant percentage of patients who opt for physician-assisted suicide in Oregon eventually die of natural causes, but they have the assurance that if their suffering were to become unbearable, they would be assisted with dying.

Abuse is possible in all human activities and practices. It follows that opponents of assisted dying have a moral responsibility to factor in the possible abuse of patients at the end of life who are denied assistance with dying.

So, the claim that assisted dying is somehow *unique* or *different* from other end-of-life decisions – since it *alone* would make society or medical practice slide down a slippery slope towards unintended forms of killing, thus eroding our respect for human life – lacks evidence.

Still, the Nazis' "euthanasia" programme before and during the Second World War is often cited as proof that legalising assistance with dying would place society on a slippery slope to something unthinkably bad. [13] Before the war, Nazi Germany did indeed embark upon a pro-

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Dignity Act on 27 October 1997. In November 2008, residents of the state of Washington voted 68% to 42% in favour of a *Death with Dignity Act*.

[12] A proper study of an alleged slippery slope in respect of end-of-life decision-making would need to look at other countries too, such as the Netherlands, Belgium and Luxembourg, where voluntary euthanasia is legal, and Switzerland, where assisted suicide is legal. This would assist with building into legislation the most effective safeguards against abuse. Importantly, the 2011 report by a Canadian Expert Panel found that the "much-feared slippery slope has not emerged following decriminalization, at least not in those jurisdictions for which evidence is available." See Udo Schüklenk *et al*: *op. cit.*, at p 65.

[13] Arthur Caplan, Australia Goes First, in Arthur Caplan, *Due Consideration: Controversy in the Age of Medical Miracles*. New York: John Wiley, 1998, pp. 225-226. For discussions of the Nazi analogy, see Tom Beauchamp and James Childres, Principles of Medical Ethics (fourth edition). New York and Oxford: Oxford University Press, 1994, pp 231-2;

gramme of non-voluntary "euthanasia" for defective infants. The programme expanded to non-voluntary and involuntary euthanasia of adults with mental and physical disorders. It was embedded in an ideology of the superiority of the *Herrenvolk*, and the motive was racial purity. It was state-sanctioned mass murder, not euthanasia − where death is voluntarily requested and in the interest of the person who dies. It was an abuse of the term 'euthanasia'. Significantly, holocaust survivors do not see any link between the Nazi "euthanasia" programme and voluntary active euthanasia in a caring healthcare setting.[14]

Survey of medical doctors' attitudes: The ethics of assisted dying (doctor-assisted suicide and active voluntary euthanasia)

Having looked at these ethical arguments for and against assisted dying, it is interesting to note the persuasions of South African medical practitioners. In the 2011 scoping survey,[15] two out of every five respondents (40%) either affirmed that, or were uncertain whether, they would *administer a lethal drug upon request* (perform voluntary active euthanasia). This percentage rose marginally to 43% when respondents were asked whether they would *provide the means to enable assisted suicide*. This is an indication that respondents believe the two forms of assisted dying – doctor-assisted suicide and voluntary euthanasia – to be, ethically speaking, similar or identical.

Very significantly, however, when respondents were asked whether they could imagine a future illness bad enough that they themselves would commit assisted suicide, or would ask a colleague to perform voluntary euthanasia on them, this percentage rose by roughly 50% to almost two-thirds (63%).

Since unintended – foreseen and unforeseen – bad consequences are risks that attach to all human activities and practices, the constant chal-

and Keymanthri Moodley, Chapter 17, Ethics at the End of Life, in Keymanthri Moodley (editor): *op. cit.*, at pp 267-268.

[14] RD Leichtentritt, KD Rettig, S Miles, Holocaust survivors' perspectives on the euthanasia debate. *Social Science & Medicine*, Volume 48, 1999, pp 185-196.

[15] See Addendum, Figures 3, 4 and 5.

lenge is to put in place the necessary policies, structures and practices to address those risks as best we can.

In summary, the possibility of bad consequences needs to be managed through effective strategies and their implementation. And we also need to weigh the possible bad consequences – in terms of suffering and loss of trust – if assistance with dying remains unlawful as a consequence of invalid arguments or simply a blanket refusal to address the need for assistance.

5.3 A Case for Legal Reform

There should be a comprehensive bill that creates the framework for responsible end-of-life decision-making. The law should cover decision-making areas that would benefit from legal clarity, such as terminal pain management (Section 2, above), the withholding and withdrawal of potentially life-sustaining treatment (Section 3, above), and advance directives (Section 4, above).

In addition, this Position Paper supports the inclusion of assisted dying (assisted suicide and voluntary euthanasia) in such a bill. This would be the most controversial aspect of such a bill. However, a bill that excludes assisted dying would still be a significant advance on the absence of clarity in the current legal position.

Whatever the different religious, ethical, clinical and legal viewpoints we might have, *a debate about the ethics of decriminalising assisted dying is in essence a debate necessitated by the ethical imperative to interpret fundamental constitutional rights in respect of an area of human need*.

5.3.1 Assisted Dying Is Unlawful

South African law on assistance with dying is clear: it is a criminal offence.[16]

[16] SALC Report, p 68.

First, *assisting with, aiding or abetting suicide* is a criminal offence – murder, attempted murder, or culpable homicide. It has not yet been the subject of any court ruling or legislation in South Africa.[17] Attempted suicide itself is no longer a crime. [18]

Second, *voluntary (active) euthanasia* is the intentional killing of another person, which is murder, unless there is a ground for legal justification.[19] Motive – such as empathy, compassion or mercy – is not a recognised ground for legal justification of an act of killing, but it may impact on the severity of the sentence.

Following this legal position, the HPCSA "finds active euthanasia, or the wilful act by a health care professional to cause the death of a patient unacceptable, notwithstanding whether or not such an act is performed at the request of the patient or his or her closest relatives or of any other person."[20]

5.3.2 The Ethics of Legalising Assisted Dying

What is the ethics of *legalising* assisted dying? Is there a coherent ethical case to be made for *decriminalising* it? Or are there compelling ethical grounds for retaining the legal *status quo* and excluding assisted dying from a comprehensive bill on end-of-life decision-making?

The ethics of assisted dying (as opposed to the ethics of legalising it) poses a typical ethical dilemma (see Section 5.2, above) since both the cases for and against assisted dying appear to be able to muster strong ethical arguments. *We face an ethical choice between right (we should assist) and right (we should refrain from assisting).* In terms of purely ethical argument, untainted by partisan religious beliefs, the case for as-

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[17] Melodie Slabbert: *op. cit.*, p 145.
[18] *R v Peverett* 1940 AD 213; *R v Nbakwa* 1956 2 SA 557 (SR); *S v Gordon* 1962 4 SA 727 (N); *Ex parte Die Minister van Justisie: In re S v Grotjohn* 1970 2 SA 355 (A); *S v Hibbert* 1979 4 SA 717 (D).
[19] *R v Davidow* 1955 WLD unreported; *S v De Bellocq* 1975 3 SA 538 (T); *S v Hartmann* 1975 3 SA 532 (C); *S v McBride* 1979 4 SA 313 (W); *S v Marengo* 1990 WLD unreported; *S v Smorenburg* 1992 CPD unreported.
[20] HPCSA: *op. cit.*, p. 1.

sistance with dying appears to be more cogent than the case against (see Section 5.2.2, above). Still, ethical consensus is probably impossible, given different basic ethical value commitments.

The SALC says the following about this ethical dilemma: "From the submissions received it is clear that in so far as active euthanasia [assisted dying] is concerned, society is divided and moral controversy is rife. It places the SA Law Commission in the difficult position of having to clarify the principles on which legal intervention should proceed in the absence of a moral consensus on the issue."[21]

Public opinion alone cannot resolve this dilemma. In this regard, the SALC quotes Constitutional Court Judge Arthur Chaskalson who said that "public opinion may have some relevance to the enquiry, but, in itself, it is no substitute for the duty vested in the courts to interpret the Constitution and to uphold its provisions without fear or favour. If public opinion were to be decisive there would be no need for constitutional adjudication."[22]

Resolving this ethical dilemma would require *finding common ground on a level other than our different personal ethical and religious beliefs*, by interrogating the content of our common constitutional values and rights, and asking what they require from us in our constitutional democracy. Strategically, it would require shifting our conversation from our *personal* ethical and religious beliefs about what is right and wrong to the constitution's perspective about what is permissible or not for us *as citizens*.

The underlying philosophy is that *the Constitution should be understood as a mechanism* – arrived at through a national conversation and agreement – *for creating an encompassing or overarching moral community that binds together the citizens of the country around common moral values and principles*. Within the state, we are all members of

[21] SALC Report, p 140.
[22] *Idem*, p 141. *S v Makwanyane* 1995 2 SACR 1 (CC) at 431 B-D.

many overlapping moral communities (for example, the church, the workplace, a profession, a family, a circle of friends) and we are able to live our values and principles in those communities, provided doing so is legal. If, however, we hold beliefs about the arrangement of our society that meet with the strong disapproval of others, the only way to settle such disagreements would be to ask what the Constitution regards as permissible.

To put it bluntly: analogously to the Constitution giving the community of believers in polygamy permission to live according to their beliefs, the question whether the community of believers in assisted dying should be given permission to live according to their beliefs is a matter of constitutional interpretation. This is what the ethics of decriminalising assisted dying is about.

There are many different kinds of situations illustrating the need for decriminalising assisted dying. In these situations, such as in Case Study 3, below, terminal pain management, withholding and withdrawal of potentially life-sustaining treatment, and advance directives appear to be jointly incapable of giving adequate expression to a cry for compassionate assistance.

The best pain management may be inadequate to control pain and distress. Some might argue that more effective sedation should be administered. If light, palliative sedation proves ineffective, as it did in the case of this young woman, deep, terminal sedation, with cessation of artificial nutrition and hydration, would enable her to die naturally and completely free from any pain and distress. But her voluntary preference was for assistance to die immediately.

The ethical question – which leads to an ethical stalemate – is this: Why should we not respect her free choice and help her, given that her suffering is all-consuming and her death imminent? The question about the ethics of legalising assisted dying, is this: *Could an appeal to the spirit and rights of our Constitution resolve this ethical stalemate?*

Case Study 3: Young woman dying of ovarian cancer (adapted from a real-life case[23])

A 20-year-old woman is dying of ovarian cancer. She is suffering from unrelenting vomiting, apparently as the result of sedation. Her breathing is loud and laboured. She is emaciated, her eyes are hollow, and she appears much older than 20. She is receiving nasal oxygen, has an IV, and is sitting in bed suffering from what is obviously severe air hunger. She weighs 37 kilograms, has suprasternal and intercostal retractions with her rapid inspirations, has not eaten or slept in two days, has not responded to chemotherapy, and is being given supportive care only.

When her illness had initially turned for the worse, she discussed at length, with her attending physician and closest family, what her preferences would be should her disease progress to this point. Her mother sits with her, holding her hand. The young woman's physician enters the room. Her only words are, "the time has come". She looks at her mother, who nods.

5.3.3 Interpreting the Constitution – The Right to Life

The SALC Report contends that "the only way in which an answer will present itself is if the discussion could be conducted with total objectivity in terms of the constitutional principles."[24] Specifically, it argues that the constitutional debate will hinge on an *interpretation of the constitutional right to life*. In its most basic form, the right to life is a guarantee to citizens that they have a right 'to be alive'. Since a law authorising a limitation of the right to life does not necessarily amount to an extinction of that right (as was the case with legalising termination of pregnancy or abortion), it follows that a law authorising assisted dying may be a reasonable and justifiable limitation on the right to life. Thus, "the constitutional survival of the proposed legislation [on assisted dy-

[23]Anonymous author: It's Over, Debbie. *Journal of the American Medical Association (JAMA*), Volume 259, Number 2, 8 January 1988, p 272.
[24] SALC Report, p 141.

ing] will therefore depend on whether the Court gives 'life' a content value, importing some form of *quality of life* beyond mere existence; secondly whether it accepts that there are circumstances in which a person's quality of life has *degenerated* to such an extent that to prolong the dying process runs counter to the right to life guarantee; and thirdly, to what degree the *other rights* of a terminally ill patient embody values of an open and democratic society which would justify a limitation of the right to life in circumstances where a person is little more than alive" (emphases added).[25]

Legal academics Prof Pieter Carstens (Professor of Criminal and Medical Law, University of Pretoria) and Dr Debbie Pearmain[26] make the same point about the constitutional right to life (section 10 of the Constitution) being pivotal to the constitutionality of assisted dying. In the case of termination of pregnancy, the right to freedom of choice and the right to bodily integrity are justifiable limitations to any other right that may be infringed by such an act, provided there is compliance with all regulations. The anomaly is that, *given a right to life, there is no right to die that would be the equivalent of the right to abortion*.

One could say that having a right to life does not entail that one has a *duty to live*, regardless of circumstances. In this regard, two references in the Constitutional Court case of *Makwanyane*[27] are important. First, Judge Kate O'Regan said the following: "The right to life, thus understood, incorporates the right to dignity. So the rights to human dignity and life are entwined. The right to life is more than existence, it is a right to be treated as a human being with dignity: without dignity, human life is substantially diminished. Without life, there cannot be dignity" (par 327).

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[25] *Idem*, p 141-2.
[26] Pieter Carstens and Debbie Pearmain: *Foundational Principles of South African Medical Law*. Durban, Johannesburg, Cape Town: LexisNexis, 2007, p 202.
[27] *S v Makwanyane* 1995 2 SACR 1 (CC).

In short, the crucial point here is that *the right to life involves biological or physical life coming up to a certain standard – having a certain quality or good – and this point is captured by the notion of life having dignity and being treated with dignity*.

Second, Judge Ismail Mahomed asked the following questions (par 268): "Does the 'right to life', within the meaning of section 9 [of the Constitution], preclude the practitioner of scientific medicine from withdrawing the modern mechanisms which mechanically and artificially enable physical breathing in a terminal patient to continue, long beyond the point, when the 'brain is dead' and beyond the point when a human being ceases to be 'human' although some unfocussed claim to qualify as a 'being' is still retained? If not, can such a practitioner go beyond the point of passive withdrawal into the area of active intervention? When? Under what circumstances?"

Carstens and Pearmain[28] put the constitutional position of assisted dying as follows: "legalising euthanasia in South Africa, in the constitutional paradigm, will only be possible if such a practice is regarded as a justifiable and reasonable limitation on the right to life in terms of section 36 of the Constitution. Conversely, the criminalisation of euthanasia will imply a justifiable limitation to the right to dignity, freedom of bodily integrity and privacy… (A) central tenet of contemporary South African medico-legal doctrine is the notion of patient autonomy, that is, the right of a competent adult to determine what shall be done to his or her body." In South Africa, this right to personal autonomy has its legal roots in both the common law and certain constitutionally protected rights to dignity, privacy and freedom of bodily integrity.

Ultimately, *at issue in the ethics of decriminalising assisted dying is the moral imperative that law and public policy in the democratic state should establish a responsible balance between respect for personal*

[28] Pieter Carstens and Debbie Pearmain: *op. cit.*, p 202.

conscience (individual autonomy) and the pursuit of the public good (state interest).

Controversy should not deter us from exploring public-policy options with intellectual honesty. Following the first democratic election of 1994 and the adoption of the new Constitution in 1996, we have made a fresh start that enabled us to be bolder than most others states in rewriting some of our society's ground rules. Among others, we decriminalised termination of pregnancy (abortion) and abolished capital punishment, both probably in the face of majority popular opinion, but faithful to the ethical demands of the Constitution.

Our point of departure should be the bill of rights of the Constitution, which recognises not only the right to life, but also that every person has inherent dignity and has a right to have that dignity respected, as well as other relevant constitutional rights. Although the question regarding the constitutionality of assisted dying has not been decided by the Constitutional Court as yet,[29] the court has already asked that question (per Judge Mahomed). It would be fair to say that should the court decide the issue, quality-of-life considerations and the right to dignity would inform the content of the right to life and balance it against other rights.

So, the key question is this: *can our constitutional rights be interpreted in such a way that assistance with dying – assisted suicide and voluntary euthanasia – could, or even should, be decriminalised within clearly defined parameters?* Significantly, Carstens and Pearmain conclude their discussion of the legal position in respect of assisted dying as follows: "(T)he underlying values, spirit and purport of the applicable sections of the Constitution [sections 10, 12 and 14], seem to be supportive of the introduction of voluntary euthanasia in South Africa."[30]

[29] SALC Report, p 115.
[30] Pieter Carstens and Debbie Pearmain: *op. cit.*, p 210.

5.3.4 Common Law and Case Law

Common-law definitions of criminal offences guiding our case law appear to be inadequate to do justice to the underlying ethical values that inform assistance with dying. They lack the necessary sensitivity for specific circumstances in which persons may wish to claim their right to exercise autonomous choices regarding their suffering and continued life.[31] They leave inadequate legal space for assisting someone to die for their own good, and when that is based on free and rational preference, without risking criminal or civil liability. There is insufficient legal recognition of the fact that life may have such a low quality that death becomes the only escape from all-consuming, irreversible suffering.

Our case law illustrates inner tensions with regard to assistance with dying. See Case Study 3.

Case Study 4: The *Hartmann* [32] Case

Dr Hartmann, a general practitioner, administered a lethal dose of pentothal to his 87-year-old father, who was dying of terminal cancer and had been suffering a great deal of pain. The father died within seconds. He had not expressed a wish to die, but the presiding judge indicated that even if he had, that would not have constituted a defence.

Dr Hartmann was convicted of murder and sentenced to imprisonment for a year. The sentence was suspended in full from the "rising of the court" – from the time the judge left the courtroom.

By passing such a lenient sentence, the court held that the compassionate motive with which euthanasia (assisted dying) had been perpetrated was an extenuating circumstance, hence the extremely lenient sentence.[33] It could be argued that by passing a symbolic sentence, the

[31] This point came out vividly in the trial of Prof Sean Davison in New Zealand in 2011 (see Section 1.1, above). Both parties and the judge acknowledged this point. Also see Footnote 78 and the accompanying discussion.
[32] *S v Hartmann* 1975 3 SA 532 (C).
[33] This is a consistent trend also found in other cases. See Melodie Slabbert: *op. cit.*, p 140.

judge in the *Hartmann* case recognised that our legal categories are inadequate for the uniqueness of assistance with dying (in this case non-voluntary euthanasia), which should not constitute murder.

It is impossible to know the extent to which medical practitioners, family members or friends assist patients with suicide or practise voluntary euthanasia. It remains under the radar, but it certainly happens despite the risk. No doubt the treatment of pain and suffering often directly intends death.

5.3.5 Reopening the Legalisation Debate

Are we content to remain silent about the criminality of these practices, or is it better to confront their legality head-on? There are strong arguments on both sides, and they should be heard in public.

Internationally, this debate has been advanced considerably, albeit in quite different ways, since the publication of the SALC Report in November 1998 – in the United States,[34] the Netherlands,[35] Belgium,[36] Luxembourg,[37] Switzerland,[38] the United Kingdom[39] and Canada.[40] Evidently, the trend is towards careful, measured liberalisation of the law.

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[34] The states of Oregon (1997) and Washington (2008) decriminalised physician-assisted suicide after state referendums. In the state of Montana there is nothing in Montana Supreme Court precedents or Montana statutes indicating that physician aid in dying is against public policy. Consequently, a terminally ill patient's consent to physician aid in dying constitutes a statutory defence to charge of homicide against the aiding physician when no other consent exceptions apply. See Udo Schüklenk *et al*: *op. cit.*, at pp 69-73.

[35] The Dutch *Termination of Life on Request and Assisted Suicide (Review Procedure) Act of 2002* states that although these practices remain, in principle, criminal offences, physicians will not be prosecuted if they have reported to a review committee and the committee finds that they have acted with due care. See Udo Schüklenk *et al*: *op. cit*., at p 56. Apart from reporting, compliance criteria concern the patient's request, the patient's suffering (unbearable and hopeless), the information provided to the patient, the presence of reasonable alternatives, consultation of another physician and the applied method of ending life. http://en.wikipedia.org/wiki/Euthanasia_in_the_Netherlands

[36] Voluntary euthanasia is legal in Belgium in terms of *The Belgian Act on Euthanasia of May, 28th 2002* that came into effect on 23 September 2002. http://www.kuleuven.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23 The Act does not consider assisted suicide at all. As in the Netherlands, terminal illness is not a necessary condition for voluntary euthanasia to be lawful in Belgium.

[37] In March 2009, Luxembourg decriminalised both voluntary euthanasia and assisted suicide. http://en.wikipedia.org/wiki/Legality_of_euthanasia

Mindful of Judge Chaskalson's views about the limited relevance of public opinion for constitutional interpretation,[41] some anecdotal evidence[42] suggests that in South Africa the time has come to reopen the public debate about decriminalising assisted dying, kept on hold since 1998.

It is probably fair to say that sensitive people, who come to know the tragic circumstances in which assistance with dying is contemplated, increasingly believe that we need to create the legal space for assisted dying. Opting for assisted dying should be everyone's personal, free choice, based on an assessment of one's suffering and loss of dignity, but within clearly defined legal boundaries.

Opponents of liberalising our law are entitled to insist that no pressure or duress should taint a free and informed decision about one's own continued existence. But they should also accept that others are entitled to make personal choices of which they disapprove, provided they are respectful of the law.

The current legal position creates situations that are unjust and lack compassion. See Case Study 3. A ruling by the Constitutional Court in

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[38] Assisted suicide is legal in Switzerland, but not voluntary euthanasia. Foreign nationals may also receive assistance with suicide, at organisations such as Dignitas. http://en.wikipedia.org/wiki/Assisted_suicide

[39] In the United Kingdom, assisted dying is firmly on the public agenda, following, for example, the report of, and support for, the assisted suicide by Michelle Broad, wife of the former English international cricketer Chris Broad, who supported her choice publicly. (Their son, Stuart Broad, is a current international English cricketer.) In 2011, "the Director of Public Prosecutions issues revised guidelines setting out the factors that make the prosecution of someone who helps a loved one die less likely. Chief among them was the finding that the suspect acted out of compassion" (*The Telegraph*, 18 April 2011).

[40] In 2011, the Royal Society of Canada Expert Panel on End-of-Life Decision-Making recommended that assisted suicide and voluntary euthanasia be legalised. See Udo Schüklenk *et al*: *op. cit.*, at pp 69-73.

[41] See Footnote 72.

[42] Numerous phone-in radio and television programmes, as well as informal surveys, suggest a trend towards more progressive thinking about assisted dying.

the *Soobramoney* case has the effect that the state, in certain circumstances, may be inconsistent if it denies a request for assisted dying.[43]

Given that the state may legitimately withhold resources necessary for continued life from Mr Soobramoney, it would be inconsistent, as well as cruel, if the state were also, hypothetically, to deny the "condemned" man's request for assistance with dying, thus enabling him to die a few days sooner and with less suffering. On what grounds could the state sanction death when it is a bad for the appellant, but deny it when it is a good, especially if the state has made death the only option?

Case Study 5: The *Soobramoney*[44] Case

Mr Soobramoney, the appellant, in the final stages of chronic renal failure and having exhausted all other treatment options, claimed that he was entitled to emergency dialysis, given the constitutional right to life (section 11) and right not to be refused emergency medical treatment (section 27(3)). The court rejected this application on the grounds that withholding life-prolonging treatment, or rationing care, is compatible with a constitutional human-rights approach, given scarce resources. Withholding dialysis, a scarce resource, led directly to the appellant's death. Mr Soobramoney passed away before the conclusion of his appeal to the Constitutional Court.

Similarly, the SALC Report[45] refers to an example of a person, bitten by a dog with rabies and in the end-stage of dying, legally and mentally irreversibly incompetent, and suffering unbearable and intractable pain. Unlike a person in a PVS, as in the *Clarke* case,[46] this person cannot die a natural death free from suffering. Surely, any legal regime that

[43] This point was suggested to me in personal communication by Dr Lesley D Henley, Department of Paediatrics, Institute of Child Health, Red Cross War Memorial Children's Hospital, Cape Town.
[44] *Soobramoney v Minister of Health (Kwazulu-Natal)* CCT 32/97 (27 November 1997).
[45] SALC Report, p 213.
[46] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).

denies this person active assistance with dying is inhumane in the extreme.

So, the question is: *Should the law make provision, within clearly defined boundaries, for competent persons freely to choose assistance with dying, and for assisting incompetent persons with dying, in the terminal phase of their illness? If not, how could our law force people to die in inhumane and undignified circumstances merely to satisfy abstract legal rules,*[47] *even with optimum terminal pain management* (see Section 2.2, above). In addition, given that a denial of assistance with dying might be unconstitutional (see Section 5.3.3, above), the justification for reopening the debate about legalising assisted dying stands to reason.

5.3.6 The SALC Report's Draft Bill

We have a good point of departure for such a debate about decriminalising assisted dying, namely, the SALC Report that puts forward three options,[48] having received extensive submissions from the public in response to its earlier draft report.[49] The SALC supports Option 1 – maintaining the *status quo* in terms of which assisted dying is unlawful. Options 2 and 3 are formulated in the *End of Life Decisions Act 1998*, included as a draft bill in the Report, and are intended to serve as a basis for public discussion.

Option 1: Confirmation of the Present Legal Position

Option 1, "*the confirmation of the present legal position*"[50] (no change to the law) – the position favoured by the SALC Report – rests on the following point of departure: "Since the right to refuse medical treatment *is far removed from* the right to request euthanasia [assistance

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[47] Prof Melodie Slabbert: Unpublished presentation, "The Legal Position Relating to Euthanasia in South Africa", Department of Jurisprudence, School of Law, University of South Africa, Pretoria, 2011.
[48] SALC Report, pp 142-153.
[49] South African Law Commission Discussion Paper 71 *Euthanasia and the Artificial Preservation of Life*, April 1997.
[50] SALC Report, pp 142-143.

with dying] the Commission strongly endorses the right of the competent patient to refuse consent to medical treatment but holds that a law to permit euthanasia is unacceptable" (emphasis added).

Let us call the SALC's view the "difference thesis" − that there is a significant, perhaps unbridgeable, moral difference between *refusal* of potentially life-sustaining treatment and a *request* for assisted dying (assisted suicide and voluntary euthanasia), where the former is legally justified but the latter not. It stands in opposition to the "equivalence thesis", supported in this Position Paper (see Section 5.2.1.3, above).

The difference thesis cannot be merely asserted but needs arguments in its support. Nor can the matter be decided by majority public opinion, for the very same reasons that termination of pregnancy and abolition of capital punishment were not so decided.

Having committed to the difference thesis, the SALC Report puts forward four arguments against decriminalising assisted dying.

First, the "Commission is of the opinion that the arguments in favour of legalising voluntary euthanasia [assisted dying] as set out above are not sufficient reason to *weaken society's prohibition of intentional killing* as entrenched in section 11 of the Constitution and which is considered to be the cornerstone of the law and of social relationships" (emphasis added).[51]

The SALC does not produce any evidence for its claim that legalising assistance with dying would undermine the legal prohibition of intentional killing *in general*, thus eroding society's commitment to the special moral value of human life. If the withholding and withdrawal of potentially life-sustaining treatment does not have that consequence, why would assistance with dying? Surely, the decisive consideration is that all of these practices would take place in a compassionate, humane, merciful and controlled medical environment. It has nothing in common with killing people with the intention to harm them. One can understand

[51] *Ibidem.*

that a widespread breakdown of the civil order, in which murder is unchecked and in the public eye, would weaken society's prohibition against killing. But why would assistance with dying in a medical context, where compassion and mercy are the driving elements, have such an effect?

Without any supporting evidence, this argument has little merit. In fact, we have good evidence suggesting quite the opposite, namely that when public policy is disrespectful of human life, then, far from eroding society's commitment to the right to life, society would rally to preserve human life. Thus, civil society went right up to the Constitutional Court[52] to force government to change its policy of refusing to fund publicly the treatment of mother-to-child transmission of the HI virus.

Second, the SALC Report argues that "(w)hilst acknowledging that there may be individual cases in which euthanasia [assisted dying] may be seen by some to be appropriate, *these cases cannot reasonably establish the foundation of a general pro-euthanasia policy*" (emphasis added).[53]

At issue, however, is not whether such cases are few, but that every human being will die and may die, in the absence of a protecting and merciful law, while suffering intractable and unbearable pain and distress. Although exceptions indeed make bad law, the constant presence of terminal suffering is hardly an exception but part of the human condition.

Third, the SALC Report contends that "(i)t would be *impossible to establish sufficient safeguards to ensure that euthanasia were truly voluntary and would not inevitably lead to involuntary and compulsory euthanasia*" (emphasis added).[54] This is a factual claim, indeed three factual claims about the efficacy of safeguards against possible abuse of

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[52] *Minister of Health and others v. Treatment Action Campaign and others* CCT 8/02. available at http://www.concourt.gov.za/files/tac/tac.pdf
[53] SALC Report, p 143.
[54] *Ibidem.*

decriminalised assisted dying, namely, that there is no way to determine whether safeguards designed to eliminate bad consequences or abuse would (1) ensure that a choice is truly voluntary; (2) prevent involuntary euthanasia, and (3) prevent compulsory euthanasia.

These claims can be rebutted. Factual claim (1) – *we cannot determine whether a choice is truly voluntary* – could mean that we are never able to "get into another's head". If this is what is meant, then, of course, the whole of criminal law, premised on voluntariness, accountability and liability, would have its foundation taken from underneath it. Our everyday understanding, even of those closest to us, as well as psychology, would be in trouble. Or is there somehow a difference between voluntary and "truly" voluntary and, if so, what might that be? Truth and justice would be better served by trusting our tested criteria of understanding other minds and by applying these to requests for assistance with dying, rather than by treating such requests as somehow exceptional and beyond the pale.

As for factual claim (2) that foresees a *real risk of involuntary euthanasia*, we now have significant data that was unavailable in 1998, most notably from the implementation of physician-assisted suicide in the state of Oregon,[55] where meticulous records are being kept and annual reports are open for scrutiny. And there is new data from Western Europe, where, among others, the Netherlands decriminalised assistance with dying following a public-policy understanding of non-prosecution for assistance with dying. There is no compelling evidence that assisted dying in these territories led to involuntary euthanasia – killing persons for their own good but *against their wishes*.

Factual claim (3) cites *compulsory euthanasia as a possible unpreventable consequence of legalising assistance with dying*. It is hard to imagine what this could mean other than a possible Nazi "euthanasia" scenario, with "compulsory" referring to the power of the state. This

[55] See Footnote 61.

alarmist claim requires supporting evidence. Again, even holocaust survivors dismissed a suggestion of a similarity between the Nazi programme and euthanasia in a compassionate, medical context (see Section 5.2.2.3, above). Our Constitution contains adequate checks and balances to prevent such a far-fetched doomsday scenario, especially given effective and enforced safeguards that would be built into legislation. This kind of argument hardly merits consideration in an honest public debate.

The SALC Report's fourth and last argument against decriminalising assisted dying contends that *"(d)ying should not be seen as a personal or individual affair, the death of a person affects the lives of others*. The issue of euthanasia is one in which the interest of the individual cannot be separated from the interest of society as a whole" (emphasis added).[56] Indeed, the manner in which a person dies, does affect the lives of others, *but so do their suffering and frustrated appeals for assistance*. So, the "affects" are not limited to those that the SALC chose to consider. And indeed, while balancing of individual and state interests is a core issue in a democracy (see Section 5.3.3, above), the SALC's position could imply that state interests necessarily or routinely trump individual interests, should they clash. Again, this flies in the face of the termination of pregnancy legislation.

So, Option 1, favoured by the SALC Report, says that assisted dying should remain unlawful. Of course it is a position worthy of serious consideration and debate. But the arguments in its support are weak, largely leaning on unproven factual claims made without interrogating credible evidence.

Option 2: Decision-Making by the Medical Practitioner

Option 2, "*decision-making by the medical practitioner*",[57] proposes legislation enabling a medical practitioner to assist a patient with dying

[56] SALC Report, p 143.
[57] *Idem*, pp 143-146.

by "administering" (voluntary euthanasia) or "providing" (physician-assisted suicide) a "lethal agent", provided certain safeguards,[58] aimed at preventing abuse, are met.

Option 2 poses two further points for debate. First, its wording, namely, that a medical practitioner "*shall* give effect to the request" (emphasis added), may suggest that medical practitioners have no choice but to honour the patient's request for assistance with dying if the safeguard conditions are met. By contrast, South Africa's termination of pregnancy legislation[59] as well as Option 3 (below) state that a medical practitioner "may" act on a patient's request, thus affirming an implicit conscience clause. Second, Option 2 does not mention mental or dementing illnesses, but the reference to "intractable and unbearable suffering" probably covers these.

Option 2 can be strongly defended ethically, using the ethical arguments in Section 5.2.1 (above). It also may have considerable constitutional force, but this question has not (yet) been decided by the Constitutional Court (see Section 5.3.3, above).

Within Option 2, there are possibilities that may be ethically preferable to maintaining the legal *status quo* that outlaws all forms of assisted dying (Option 1). For example, although there is no intrinsic ethical difference between assisted suicide and voluntary euthanasia, *a public policy that decriminalises only assisted suicide (or, more narrowly, doctor-assisted suicide) may be a pragmatic legislative compromise if legalising voluntary euthanasia would meet formidable resistance*. However, it

[58] These safeguards include: the patient must be suffering from terminal or intractable and unbearable illness; be over 18 years of age; mentally competent; be informed of the illness, its prognosis and available care and treatment; make a request that is free and considered; and repeat the request twice, without contradiction and at least seven days apart. At least 72 hours should pass between the final request and carrying it out; the relevant certificate with the request must be signed and witnessed by a medical practitioner; if relevant, an interpreter must be present to communicate the patient's request; and ending the patient's life must be the only way to end the suffering (presumably short of terminal sedation: and only a medical practitioner may end life. See SALC Report, pp.143-146 (art 5(1)-(8) of the draft bill).

[59] *Choice of Termination of Pregnancy Act, 92 of 1996.*

may be unfair and crueller to some patients to decriminalise assisted suicide only, and not also voluntary euthanasia. Patients in the terminal phase of amyotrophic lateral sclerosis (ALS) may be unable to commit suicide due to paralysis, with death by asphyxiation a real possibility, while other terminal patients may have the necessary mobility to commit assisted suicide.

Option 3: Decision-Making by a Panel or Committee

Option 3, "*decision-making by a panel or committee*",[60] proposes that euthanasia (assisted dying) be regulated through legislation permitting a multi-disciplinary ethics committee to consider requests for euthanasia on the basis of set criteria. This option draws from the practice in the Netherlands prior the passing of assisted-dying legislation some years after the release of the SALC Report.

Option 3, while certainly preferable to the legal *status quo*, is an unnecessarily cumbersome response to a request for assistance with dying. First, who would constitute an ethics committee and how would it function? Who elects or appoints the committee? Could someone who is in principle opposed to physician-assisted suicide and voluntary euthanasia serve on such a committee? How would decisions be taken, for example, by majority vote or consensus? Second, should not a provision be made to appeal the decision of an ethics committee? Third, and most significantly, it raises issues of distributive justice.[61] Since a committee approach is premised on the availability of additional resources, it could lead to discrimination against patients in areas with poor access to healthcare facilities. Ethics committees, whose membership requires, among others, three medical practitioners, a lawyer, and a member of a multidisciplinary team, are likely to be limited to tertiary, and therefore urban centres, while rural areas may not have an "ethics capacity".

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[60] SALC Report, pp 146-153.

[61] This point was brought to my attention by Dr Lesley D. Henley, Department of Paediatrics, Institute of Child health, Red Cross War memorial Children's Hospital, Cape Town.

In the final analysis, Option 3 would be an unjustifiably paternalistic approach that would take control away from the patient and medical practitioner and transfer it to a group outside the more intimate doctor-patient relationship. Attending medical practitioners can display the same caution and circumspection as a committee, and, together with patients and their families they would be able to focus on the tragic choices at hand, while avoiding general debates about the ethics of an already decriminalised practice, which may be the fate of an ethics-committee approach.

Issues to Be Clarified if the Legalisation Route is Followed

If legalising assisted dying follows the Option 2 route – which is what this Position Paper argues – a number of issues would need *further discussion to settle the boundaries of what should be legally permissible,* such as the following:[62]

- Should the ethical argument that there is no intrinsic ethical difference between assisted suicide and voluntary euthanasia have any bearing on legislation? In other words: *should an attempt to decriminalise assisted dying adopt an incremental approach, targeting assisted suicide only?* The SALC Report[63] argues that although there is no general intrinsic moral difference between these two assisted-dying practices, there is in practice an important evidentiary difference, with assisted suicide being a better test of the voluntariness of a person's choice to die. However, the report concludes that both are, legally speaking, versions of active euthanasia (assisted dying) and should be dealt with accordingly. By contrast, the states of Oregon and Washington in the United States decriminalised only assisted suicide in a ballot initiative.

[62] I discuss these in some detail in Willem A Landman: A Proposal for Legalizing Assisted Suicide and Euthanasia in South Africa, in Loretta M. Kopelman, Kenneth A. De Ville (eds.): *Physician-Assisted Suicide.* Dordrecht, The Netherlands: Kluwer Academic Publishers, 2001, pp 203-225.
[63] SALC Report, pp 79-80.

- *Non-voluntary euthanasia* of incompetent adults and seriously and irreversibly defective newly born infants is arguably more controversial than voluntary euthanasia. Their legal position should be clarified in comprehensive end-of-life legislation.
- In a request for assistance with dying, should the *illness at issue* be a terminal illness or should an intractable and unbearable illness also be a ground for a request, that is, "a bodily disorder that (1) cannot be cured or successfully palliated, and (2) that causes such severe suffering that death is preferable to continued life"?[64] Significantly, both Options 2 and 3 of the SALC Report's draft legislation refer to "terminal or intractable and unbearable illness".[65] So the question is: *should a request for assistance with dying also be an option for persons who are neither terminal nor in physical pain?* Among others, this question relates to (1) persons who have a terminal disease but are not yet in the terminal phase, for example, an ALS patient, and (2) persons suffering from acute chronic depression, a dementing disease or mental disorder, but are nevertheless competent to decide about their own continued existence. Significantly, neither Option 2 nor Option 3 – that would decriminalise assisted dying – insists on a patient being terminally ill but also recognise "intractable and unbearable illness".
- Strictly legally enforced *safeguards*[66] to prevent undesirable consequences or abuse of decriminalised assisted dying would need to be carefully formulated. In addition, *slippery-slope considerations that might be peculiar to South Africa* would need to be debated head-on. For instance, South Africa's multiculturalism and consequent risks of miscommunication; educational deficits that might compromise adequate understanding of assisted dying; differential access to

[64] D Benatar, SR Benatar, R Abratt, R. et al: *Comments on the Draft Bill on End-of-Life Decisions*, Department of Medicine, University of Cape Town, Cape Town, 1997, p 2.
[65] SALC Report, pp 143 and 148.
[66] See Footnote 108.

scarce, quality healthcare resources (for example, poor public hospitals) and consequent lack of distributive justice; and a history of racial discrimination and consequent distrust and fear of abuse.

- Who should *assist with dying*? Should close family or friends be allowed to assist with dying under professional supervision? Both Options 2 and 3 require that only medical practitioners may assist with dying.
- The legal position of *mature, competent minors* would need clarification. Option 2 is open for patients over the age of 18, but, significantly, Option 3 does not have this limitation. Legislation subsequent to the SALC Report lowering the age of competence would need to be taken into account.

Survey of medical doctors' attitudes: The need for legalising assisted dying (doctor-assisted suicide and active voluntary euthanasia)

In the 2011 scoping survey of South African medical practitioners, respondents were asked two questions about the need for legalising assisted dying.[67] When asked whether *doctor-assisted suicide* should be legalised, 51% said no, while 49% strongly agreed, agreed or were neutral. When asked whether *voluntary active euthanasia* should be legalised, these percentages changed to 53% (no) and 47% (strongly agree, agree and neutral) respectively, again indicating that these two practices were regarded as the same.

An overwhelming 81% indicated that assisted dying should only be contemplated when a patient is terminally ill, whereas a significant one in eight (12%) felt that assisted dying does not require terminal illness.

Significantly, one-third (34%) of respondents indicated that in the course of their medical practice patients had *requested* them to hasten their death.[68]

In summary, we have very persuasive ethical and constitutional grounds for debating and seriously considering the inclusion of assisted dying – assisted suicide and voluntary euthanasia – in comprehensive

[67] See Addendum, Figures 7 and 8.
[68] See Addendum, Figure 6.

end-of-life decision-making legislation, together with provisions clarifying the legal position in respect of terminal pain management, the withholding and withdrawal of potentially life-sustaining treatment, and advance directives.

6

CONCLUSION

This Position Paper argues the putting before Parliament of a comprehensive end-of-life decision-making bill in respect of the following four healthcare and medical practices, each recognising a moral right of a terminally ill person, and a corresponding moral obligation of interested parties, such as caregivers, family, and the state:

- Terminal pain management (Section 2) – the right to be free from unnecessary suffering;
- Withholding and withdrawal of potentially life-sustaining treatment (Section 3) – the right to a natural death;
- Advance directives (Section 4) – the right to future control over one's body; and
- Assisted dying – Assisted suicide and voluntary euthanasia – the right to assisted dying (Section 5).

Whereas the first three practices are relatively uncontroversial and should be guided by the applicable standard of care for responsible medical practice, South African law is not sufficiently clear to provide adequate guidance and protection for medical practitioners and substitute healthcare decision-makers. This can be rectified by means of appropriate legislation, creating an enabling environment for making the best end-of-life decisions.

The fourth, assisted dying (assisted suicide and voluntary euthanasia), is unlawful in South Africa and can only be decriminalised through legislative reform. There are strong arguments to suggest that such legis-

lation would be consistent with the letter and spirit of the Constitution's bill of rights, if not required by it, as was the case with termination of pregnancy legislation. So, a key question is: *in terms of the Constitution, what can a terminally ill person in the end-stage of a terminal illness legitimately ask of others who are willing and able to assist with dying?*

Quite understandably, some would regard assisted-dying legislation as unnecessary and undesirable since the other three end-of-life healthcare practices provide adequate options to care for the dying. The counter-argument, however, is persuasive: people justifiably want greater control over the time and manner of their death. In so far as it is within their control, they elect not to die in a drug-induced state of semi-consciousness or unconsciousness. They regard refusal of assistance with dying as a denial of their personal autonomy and dignity, lacking compassionate recognition of their suffering. And they do not regard recognition of their autonomous preferences as anti-community or selfish.

Those who find such assistance with dying an affront to their personal conscience or religious beliefs should consider that we live in a constitutional democracy which seeks to balance individual and state interests. Consequently, what some regard as unethical may not be unlawful. On the contrary, *there may be an ethical as well as a constitutional duty to decriminalise a practice that some regard as unethical*. This is part of the trade-off of living in a heterogeneous society. And even though our democracy is young and still taking shape amidst great challenges, we have been brave and progressive in many other areas of social reform. There is no reason why it should be any different in respect of end-of-life decision-making.

In summary, this Position Paper argues that *there should be a public debate on end-of-life decision-making, resulting in a comprehensive end-of-life decision-making bill, along the lines of the draft bill* – End of Life Decision Act 1998 – *included in the SALC Report of 1998*.

Finally, the following statements summarise key elements of this Position Paper's perspective on the ethics and law of end-of-life decision-making:

- Life is finite and may reach a point where death is a good (benefit) rather than a bad (evil).
- We exercise autonomous control over our bodies and healthcare throughout our lives, and it should be no different at the end of life.
- We have a moral and constitutional right to life, but there is no overriding duty to live.
- We have a moral right to a peaceful and dignified death, free from terminal pain and distress, and this right is compromised by some forms of end-of-life healthcare interventions.
- We have constitutional rights consistent with this moral right to a peaceful and dignified death.
- Treatment – including artificial nutrition and hydration – in opposition to the will of the patient, or the patient's substitute decision-maker, is ethically and legally unjustified since we have a right to refuse – contemporaneously or through an advance directive – any treatment, including potentially life-sustaining treatment, and others – also close family members – have a duty to withhold or withdraw treatment that is refused.

In precisely defined conditions, we have an ethical and – arguably – a constitutional right to be assisted with dying – by being supplied with the means to commit suicide, or by having one's life terminated. Persons who wish to assist with dying have a corresponding right to do so.

ADDENDUM:
SURVEY OF MEDICAL DOCTORS' ATTITUDES TO ASSISTED DYING

In 2011, the Ethics Institute of South Africa (EthicsSA) conducted a scoping survey on end-of-life decision-making among 120 medical practitioners (doctors and specialists) at the medical schools of the University of Pretoria and the University of the Free State. Ethical approval for the research was granted by the South African Medical Association Research Ethics Committee (SAMAREC). The medical practitioners were intensivists (ICU), oncologists, physicians, trauma surgeons, general surgeons, orthopaedic surgeons, neurologists, family physicians, urologists, general practitioners, psychiatrists, gynaecologists, haematologists, ophthalmologists, and dermatologists.

1. Demographic Information

The vast majority of respondents are religious.

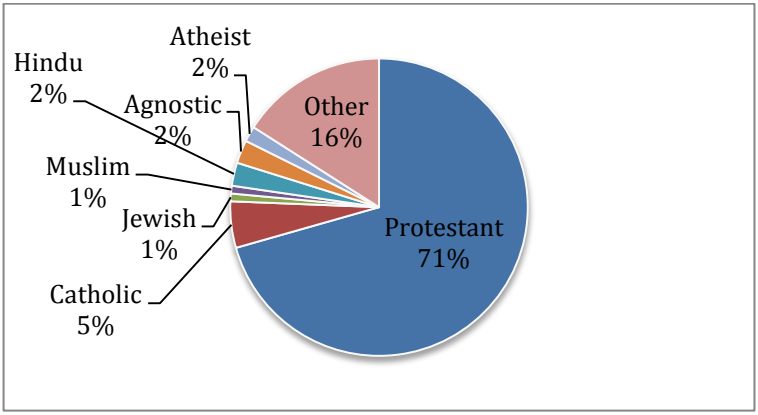


Figure 1: Religious affiliation

Over 70% indicated that they were Protestant (see Figure 1, above) and an overwhelming majority of 77% indicated that they were either very religious or religious (see Figure 2, below).

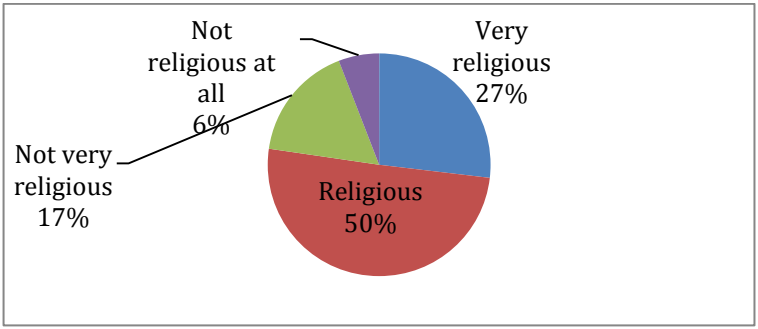


Figure *2:* Are you religious?

2. The Ethics of Assisted Dying

Respondents were asked three questions about the ethics or "acceptability" of assisted dying (assisted suicide and voluntary active euthanasia) if it were to be legal.

Two out of every five respondents (40%) either affirmed that, or were uncertain whether, they would *administer a lethal drug upon request* (perform voluntary active euthanasia) (see Figure 3, below). This percentage rose marginally to 43% when respondents were asked whether they would *provide the means to enable assisted suicide* (see Figure 4, below).

This is an indication that respondents believe that the two forms of assisted dying – doctor-assisted suicide and voluntary euthanasia – are ethically-speaking similar or identical.

Very significantly, however, when respondents were asked whether they could imagine a future illness bad enough that they themselves would commit assisted suicide, or would ask a colleague to perform voluntary euthanasia on them, this percentage rose by roughly 50% to almost two-thirds (63%) (see Figure 5, below).

Question 1: (Imagine assisted dying is lawful, with safeguards.) If a competent, terminally ill patient who is rational and reflective repeatedly asks you to inject drugs to end his or her life, are there any situations where it would be acceptable for you to give a lethal injection?

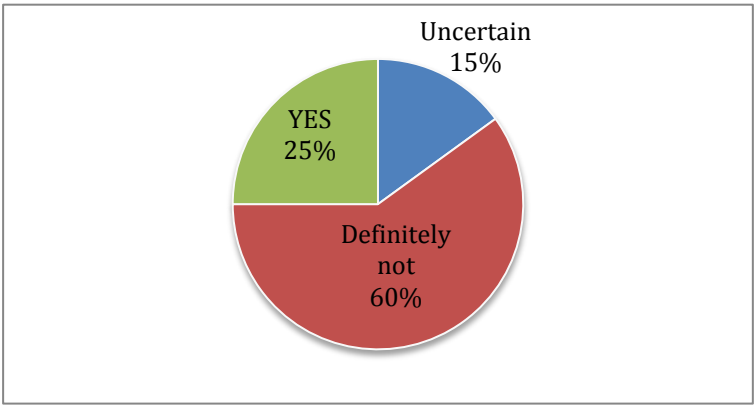


Figure 3: The ethics of doctor-assisted suicide

Question 2: (Imagine assisted dying is lawful, with safeguards.) If a competent, terminally ill patient who is rational and reflective repeatedly asks you to prescribe drugs so the patient can end his or her life by overdose, are there any situations where it would be acceptable for you to prescribe the drugs needed?

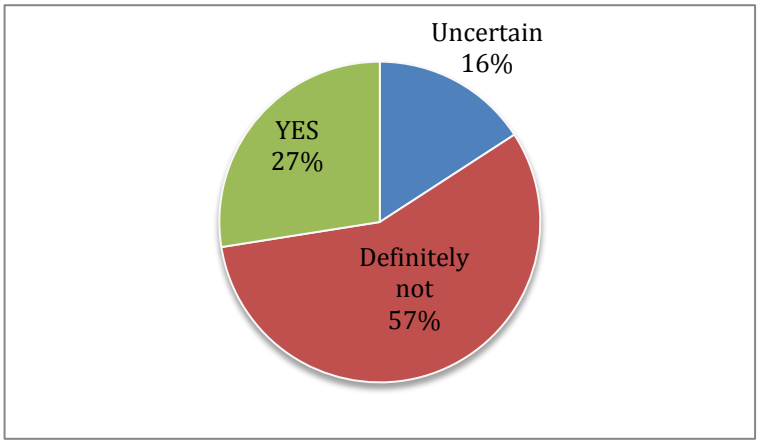


Figure 4: The ethics of voluntary active euthanasia

Question 3: (Imagine assisted dying is lawful, with safeguards.) Can you imagine any future illness bad enough that you might wish either to self-prescribe medications to end your own life intentionally or to have a colleague intentionally end it for you?

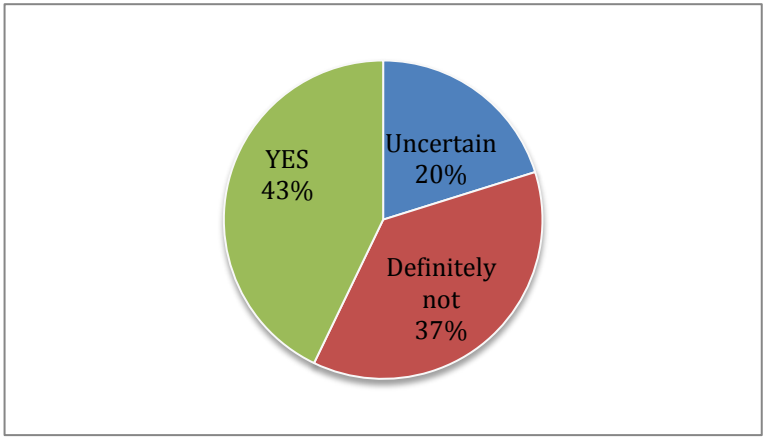


Figure 5: Medical practitioners choosing assisted dying for themselves

3. Patient Requests for Hastening Death

One-third (34%) of respondents indicated that in the course of their medical practice patients had *requested* them to hasten their death (see Figure 6, below).

Question 4: In the course of your medical practice, has a patient ever asked you to hasten his or her death?

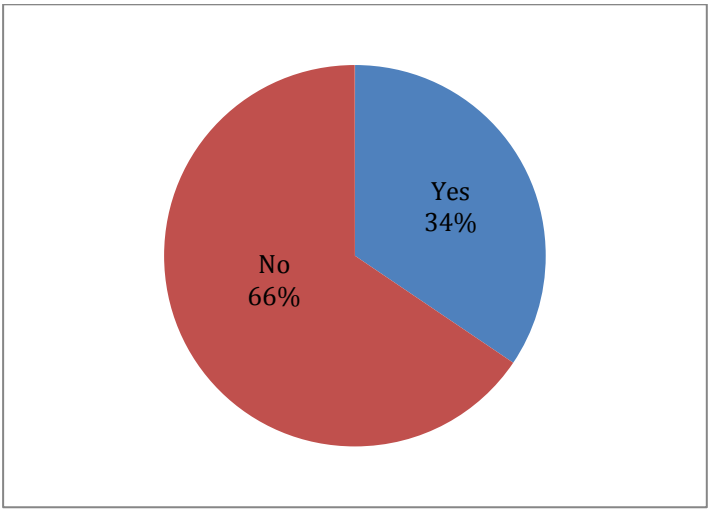


Figure 6: Patients asking doctors to hasten their death

4. The Need for Legalising Assisted Dying

Respondents were asked two questions about the need for legalising assisted dying. When asked whether *doctor-assisted suicide* should be legalised, 51% said no, while 49% strongly agreed, agreed or were neutral (see Figure 7, below). When asked whether *voluntary active euthanasia* should be legalised, these percentages changed to 53% (no) and 47% (strongly agree, agree and neutral) respectively, again indicating that these two practices were regarded as the same (see Figure 8, below).

Question 7: The law should allow a doctor to provide drugs to a rational and reflective terminally ill patient who requests assistance with committing suicide.

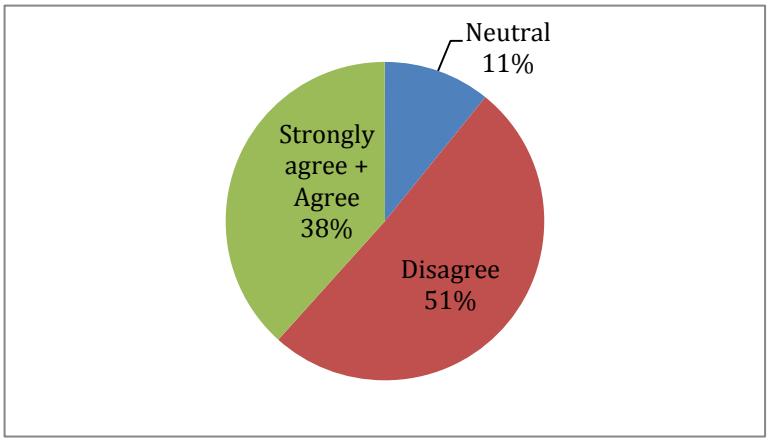


Figure 7: Legalising doctor-assisted suicide

Question 8: The law should allow a doctor actively to end a patient's life if a rational and reflective terminally ill patient asks the doctor to administer a lethal injection.

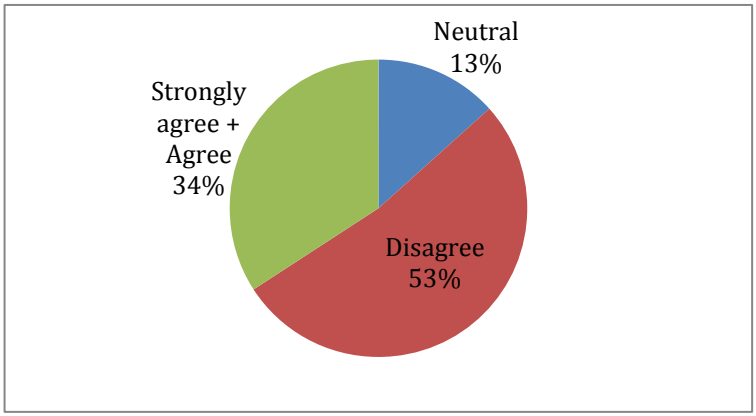


Figure 8: Legalising voluntary active euthanasia

5. Pain Management and Comfort Care

Respondents were asked two questions about pain management and comfort care. When asked whether inadequate administration of pain medication was due to *fear of hastening a patient's death*, 54% strongly agreed and agreed, 31% disagreed, while 15% were neutral (see Figure 9, below). When asked whether inadequate pain medication was due to *fear of criminal prosecution for hastening a patient's death*, the responses changed to 39% (strongly agree and agree), 40% (disagree) and 21% (neutral) respectively (see Figure 10, below).

This indicates that under-treatment of pain is a serious problem, at least in part informed by fear of criminal prosecution for hastening a patient's death in an effort to manage pain.

Question 9: Doctors fail to give adequate pain medication most often through fear of hastening a patient's death.

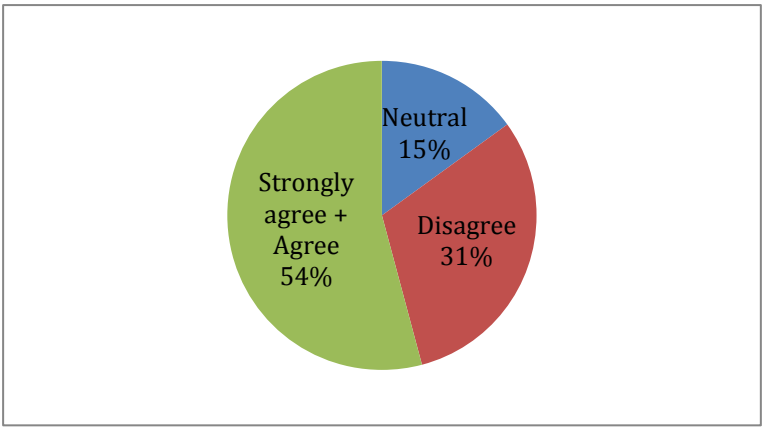


Figure 9: Under-treatment of pain for fear of hastening death

Question 10: Doctors fail to give adequate pain medication most often through fear of criminal prosecution for hastening a patient's death.

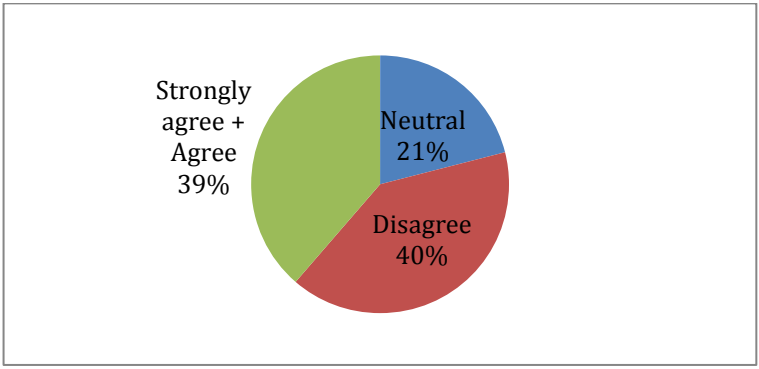


Figure 10: Under-treatment of pain for fear of criminal prosecution for hastening death

6. Terminal Illness as a Requirement for Assisted Dying

Respondents were asked if a patient with intractable and unbearable pain, but *not terminally ill*, requested them to end his or her life whether they would practise doctor-assisted dying (assisted suicide or voluntary euthanasia) if it were legal. An overwhelming 81% indicated that assisted dying should only be contemplated when a patient is terminally ill, whereas a significant one in eight (12%) felt that assisted dying does not require terminal illness (see Figure 10, below).

This last finding may be an indication that dementia or dementing illness would not be a justification for assistance with dying for the majority of respondents.

Question 11: If a patient with intractable and unbearable pain and suffering, who is not terminally ill, asks me to end his or her life, I would do so if doctor-assisted dying were legal.

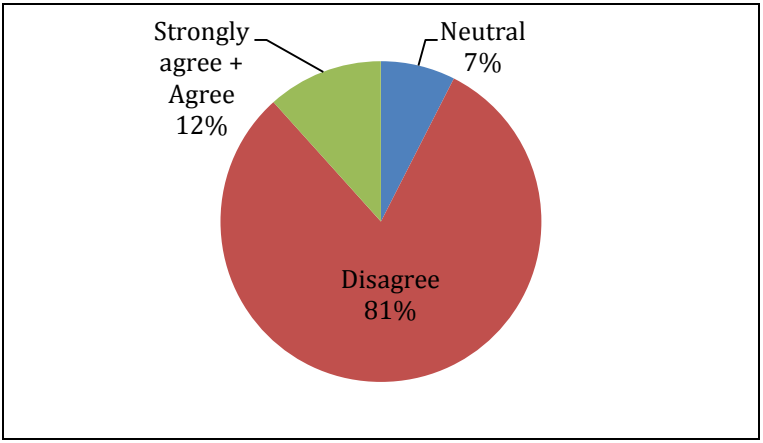


Figure 11: Terminal illness as a requirement for assisted dying

7. The Value of Advance Directives

A vast majority of 75% agreed that advance directives (living wills and powers of attorney for healthcare) assist to clarify patients' wishes regarding treatment at the end of life, or when incompetent. Only 12% disagreed (see Figure 11, below). One could expect this positive response to rise, should legislation be passed to clarify outstanding issues, accompanied by a public education campaign.

Question 12: Legalising advance directives (a living will and a health-care power of attorney) is a positive step in clarifying a patient's wishes regarding treatment at the end his or her life, or when incompetent.

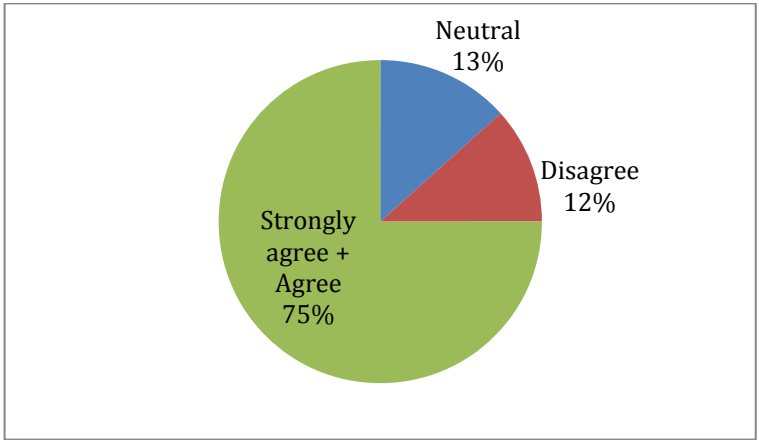


Figure 12: The value of advance directives

SURVEY

Attitudes to Assisted Dying – Medical Doctors

In 1998, the South African Law Commission (SALC) published a second report and draft legislation addressing matters such as pain management, withholding and withdrawal of life-sustaining treatment, advance directives, and assisted dying (assisted suicide and voluntary active euthanasia). The Ethics Institute of South Africa (EthicsSA) is particularly interested in doctors' opinions regarding assisted dying. The survey will assist with a research project on the ethics of legalising different forms of assisted dying.
Results were posted on EthicsSA's website (www.ethicsa.org) early 2012. A research protocol was approved by the South African Medical Association Research Ethics Committee (SAMAREC).

Most answers simply require a cross

		Yes	**Uncertain**	**Definitely Not**
1	*(Imagine assisted dying is lawful, with safeguards.)* If a competent, terminally ill patient who is rational and reflective repeatedly asks you to inject drugs to end his or her life, are there any situations where it would be acceptable for you to give a lethal injection?			
2	*(Imagine assisted dying is lawful, with safeguards.)* If a competent, terminally ill patient who is rational and reflective repeatedly asks you to prescribe drugs so the patient can end his or her life by overdose, are there any situations where it would be acceptable for you to prescribe the drugs needed?			
3	*(Imagine assisted dying is lawful, with safeguards.)* Can you imagine any future illness bad enough that you might wish either to self-prescribe medications to end your own life intentionally or to have a colleague intentionally end it for you?			

		Yes	**No**
4	In the course of your medical practice, has a patient ever asked you to hasten his or her death?		
5	Have you ever injected drugs intentionally to end a patient's life?		
6	Have you ever prescribed drugs knowing a patient intended to use them to end his or her life?		

Please indicate whether you agree or disagree with the statements below		**Strongly agree**	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
7	The law should allow a doctor to provide drugs to a rational and reflective terminally ill patient who requests assistance with committing suicide.					
8	The law should allow a doctor actively to end a patient's life if a rational and reflective terminally ill patient asks the doctor to administer a lethal injection.					
9	Doctors fail to give adequate pain medication most often through fear of hastening a patient's death.					
10	Doctors fail to give adequate pain medication most often through fear of criminal prosecution for hastening a patient's death.					
11	If a patient with intractable and unbearable pain and suffering, who is *not* terminally ill, asks me to end his or her life, I would do so if doctor-assisted dying were legal.					
12	Legalising advance directives (a living will and a health-care power of attorney) is a positive step in clarifying a patient's wishes regarding treatment at the end his or her life, or when incompetent.					

13 Specialty and related information

Intensivist/ICU		Oncologist	
Physician		Trauma Surgeon	
General Practitioner		Medical Student	
Other *(please specify)*			

14 I am …… years old.

15 I am a

Male		Female	

16 I am

Protestant	**Catholic**	**Jewish**	**Muslim**	**Hindu**	**Agnostic**	**Atheist**	**Other**

17 I am

Very Religious	**Religious**	**Not very Religious**	**Not Religious at all**

18 I work in the

Public sector	Private sector	Both

19 My home language is

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As global ethics emerges as an important answer to the common issues facing humankind, we cannot spare a reflection on the process leading to a consensus on global values. If we are to break political, economic, ideological, cultural, religious and gender-based patterns of domination in the debate on global ethics, we must ensure that all parties to the dialogue are able to express their values freely and in their own fashion.

This book provides indications of the current reflection on the hermeneutics of intercultural and interreligious dialogue on ethics, with an attempt to formulate in a decentralised manner priorities for future implementation of this dialogue. These include using our own religious resources to foster dialogue on ethics, searching in the transcendental or the holistic for a solution to moral diversity, dealing with the deep suffering caused by colonisation and neo-imperialism, and addressing the mutual challenges of traditionalism and modernism.

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Editors: Carol Cosgrove-Sacks and Paul H. Dembinski
Globethics.net Global No. 6 (2012)

The values that guide finance professionals and the core role played by trust in the modern finance industry have been the dominant themes of the best papers submitted for the Robin Cosgrove Prize since it was launched in 2006. Inviting young people to submit innovative ideas to advance ethical approaches to the world of finance in its many manifestations has stimulated a global debate on the role of ethics and integrity in finance. It is important to note that the prize was launched before the topic of ethics in finance became fashionable. It is not a reactive exercise to the current crisis. The aim is to prompt a shift in thinking throughout the world of finance – the fresh ideas submitted for the prize have global relevance.

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Benoît Girardin. Globethics.net Focus No. 5 (2012)

This book is an affirmation: Yes, ethics in politics is possible – and it pays off. It is not a naive dream. The author chooses a pragmatic approach and tests whether value-orientation can make a difference in politics and how. He presents practical cases and outlines criteria for dealing with dilemmas. He singles out four fundamental ethical values to achieve: limitation of power, effectiveness, accountability and justice. He develops a global and intercultural perspective, referring to Western and Eastern traditions and some world religions.

In a globalised, interdependent world of pluralistic societies, ethics in politics becomes a global ethics in politics. A book for practitioners such as politicians, activists and interested citizens, for debate and orientation.

Seeds for Successful Transformation. Global Ethics Forum 2012: Report, Outcomes and Follow-up 2012-2014
Globethics.net Focus No. 12 (2012)

With the ongoing turbulence in the global economy and especially the financial markets, the awareness is increasing that fundamental transformations of economy and of lifestyles are needed. Visions of a fair economy have to be combined with concrete small steps. Such seeds of transformation give hope.

The Global Ethics Forum (GEF) 2012 focused on two of the crucial challenges of transformation towards creating an ethical economy: the financial markets and sustainability after Rio+20. Over 70 speakers from all continents contributed to the search for ethical transformation, discussing concrete aspects of themes such as sustainability, financial transformation, transparency, and ethical business management. The Global Ethics Forum annual international conference is the most important part of the Global Ethics Forum Project. It is an event with multi-stakeholder participation that is global, open-minded, critical, fair, and solution oriented. GEF is not just an ordinary event – it is a sequence of global conferences combined with customised exchanges during the year, joint practical projects and specific access to documentation and publications for partners.

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The editor of the different series of Globethics.net Publications is Prof. Dr. Christoph Stückelberger, Founder and Executive Director of Globethics.net in Geneva and Professor of Ethics at the University of Basel/Switzerland.

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2 *Ethics in Politics. Why it matters more than ever and how it can make a difference. A Declaration*, 8pp, 2012. Available in English and French

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End-of-Life Decisions, Ethics and the Law

A Case for Statutory Legal Clarity and Reform in South Africa

Dying is a natural and inevitable part of life. Unless we die an unnatural death, we will go through a natural dying process. For some, it will be peaceful and dignified; for others it will be filled with pain, anxiety and suffering. We do not know which it will be. Globally, many countries are addressing assisted dying, albeit in different ways. Some have legalised assisted dying and others have set criteria for not prosecuting it.

This "Position Paper" aims at put forward an ethical case for end-of-life decision-making legislation. Such legislation would clarify areas of legal uncertainty, most notably in respect of terminal pain management, withholding and withdrawal of life-sustaining treatment (sometimes called "passive euthanasia"), and advance directives (a living will and a durable power of attorney for healthcare). More controversially, it also argues for the inclusion of assisted dying (assisted suicide and voluntary active euthanasia) in a comprehensive end-of-life decision-making bill.

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