

**College of Law and Management Studies**

**School of Law**

**Desiring Death: A Critical Analysis of Advanced**  
**Directives within the South African Legal**  
**Framework**

**BY**

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**DECLARATION:**

I declare that all work submitted is my own and even though I have made reference to other works, I have not plagiarised the work of anyone when submitting this dissertation

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## **Chapter 1: Introduction**

Socrates: “To fear death, gentleman, is no other than to think oneself wise when one is not, to think one knows what one does not know. No one knows whether death may not be the greatest of all blessings for man, yet men fear it as if they knew that it is the greatest of evils.”<sup>1</sup>

Death is no stranger to us humans. We see or hear about death almost on a daily basis, some may fear it whilst others seek to accept it. With the increasing knowledge in a society of medical diseases and treatments, end of life decisions is no more a rare occurrence. With the increase in medical technology over the years the lines that clearly defined life and death have become blurred. Previously death was viewed as a natural occurrence and accepted as the will of God by some; nowadays there are decisions that revolve around whether a person is legally dead or not. The legal definition of death is defined as “brain death” as stated in the National Health Act.<sup>2</sup> The ability to keep a person alive through prolonged mechanical ventilation and artificial feeding makes it difficult in deciding whether a person is in fact dead. This prolongation of life may not be the ideal way of living for some people and that’s when the advanced directive comes into focus.

An advanced directive can be in two forms namely that of a treatment directive whereby a competent person drafts a living will with prospective medical decisions for future treatment. The other is in the form of a durable power of attorney where a surrogate decision maker is chosen in advance by a patient to make treatment decisions. It should be noted that this dissertation shall focus on both types of advanced directives but more specifically on those that choose a surrogate decision maker. In practice doctors are more likely to abide by an advanced directive, it is when a surrogate decision maker is appointed that issues arise. The reason behind this is that in South Africa, a power of attorney usually ends when a person loses his or her mental capacity. This means that an appointed person can no longer make a health care decision on behalf of the person who is now mentally incompetent.

A living will is an advanced directive provided by a patient as a form of instruction regarding their future medical treatment, should they become unable to consent or to refuse treatment.<sup>3</sup> It

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<sup>1</sup> GMA Grube and JM Cooper *The Trial and Death of Socrates* 3 ed (2001) 27.

<sup>2</sup> In terms of section 1 of the National Health Act 61 of 2003, the moment of death is defined as “brain death.”

<sup>3</sup> D McQuoid Mason and M Dada *A—Z Medical Law* (2011) 258.

<sup>4</sup> *Clarke v Hurst No and Others* 1992 (4) SA 630 (D).

<sup>5</sup> Manto Tshabalala Msimang.

should be noted that throughout this dissertation when referring to advanced directives it would be in regard to the living will or a durable power of attorney for healthcare. Both terms shall be in reference to a statement made by a patient in regard to future medical treatment should the patient become incompetent and unable to express his or her wishes.

Within the South African legal framework advanced directives have received minimal attention indicative in the case of *Clarke v Hurst*.<sup>4</sup> Several years ago through the advice of the Late Nelson Mandela, the SA Law Commission tabled recommendations to Parliament which incorporated the concepts of physician-assisted suicide and advanced directives. However, at the time the then Minister of Health<sup>5</sup> failed to look at the recommendations but preferred rather to focus on other health issues of that time. As it stands South Africa has failed to legally recognise advanced directives. The provision of legal clarity would be beneficial in assisting patients, healthcare practitioners and family members in making important health care decisions especially in respect of withdrawal or withholding of life-saving treatment.

### 1.1. Purpose and Significance of Dissertation

The purpose of this dissertation is to promote the awareness of advanced directives. The idea is to highlight the advantages of legislative recognition of advanced directives. There is a gap that exists whereby ethically and in health care practice an advanced directive is recognized. Yet legally it is neither accepted nor rejected arguably it appears to be overlooked. In clinical practice, doctors generally abide by advanced directives; the issue arises when a health care directive includes a durable power of attorney, or when the advanced directive states one decision but the family members make another decision. In an already frustrating working environment, it can create a lot of anxiety and confusion if not dealt with through legislation. legislation would then serve as a reference point for both doctors and patients alike in respect of advanced directives and durable powers of attorney. Legally a power of attorney ends with competency when a person becomes mentally incompetent a power of attorney ends. In respect of a health care power of attorney, this has the potential to be confusing. There exists a need for legal clarity surrounding advanced directives and when they become enforceable as well as legally binding. Understandably a health practitioner may feel uncertain or fearful of litigation in a situation where a surrogate decision

maker decides to withdraw life-sustaining treatment. Issues may even arise when there are competing surrogate decision makers who may disagree on a treatment plan.

## 1.2. Objective of the dissertation

It is the aim of this dissertation to demonstrate that the legal recognition of advanced directives, namely that of durable powers of attorney for healthcare needs legal clarity within our current legal dispensation. The aim is to promote the legal recognition and the use of advanced directives within South African healthcare facilities whilst considering the resource restraints in our country. Importantly, this dissertation will look at the need for legal clarity within our own constitutional dispensation. Essentially patients who wish to draft an advanced directive should feel a sense of certainty that their wishes are recognised and respected legislatively. In order to remedy this situation, suggestions shall be put forward in order to bridge the gap between the ethically accepting position and the legal non-recognition of advanced directives in South Africa. Since South Africa does not have legislation specific to advanced directives, other countries such as the United States (it should be noted that even though the United States has a federated system, advanced directives have been given legal recognition in some form or the other within all of the States), Canada and the United Kingdom are looked at to see how they deal with advanced directives. These countries have been selected for the following reasons, certain States within the United States were the first to introduce a living will and have managed to successfully develop it over the years. Canada and the United Kingdom have recently been focusing on end-of-life decisions and considering South Africa's common law link with these countries these jurisdictions have been selected. It should be noted that mentioning these other jurisdictions serves merely as a guideline and is not binding on our legal system.

There are some questions that need clarity with regard to a durable power of attorney in healthcare:

- Would there be instances where a surrogate decision maker's decision can be overridden by another family member or a healthcare practitioner, even when it complies with the law?

- Can a surrogate decision maker decide that life sustaining treatment be removed even if it may inadvertently lead to hastening a person's death?
- How does a health care practitioner deal with two surrogate decision makers who have opposing decisions on the treatment of the patient?
- And would a health care practitioner be protected against a medical negligence claim provided that the decisions made are within the standard of care in medical practice?

### 1.3. Background

The National Health Act<sup>4</sup> provides that everyone has the right to participate in any decision affecting his or her personal health and treatment.<sup>5</sup> This can be interpreted to suggest that section 8 only affords a person the right to participate in a decision and does not appear to suggest that a person's decision should take precedent; it is merely a suggestive factor. Furthermore, the Act<sup>6</sup> does not make reference to advanced directives or living wills. It would be much easier to understand if proper terminology like living will and durable power of attorney was used in the Act<sup>7</sup> even though clarity does not stop at terminology. In addition, the National Health Regulations<sup>8</sup> alternatively does provide for the recognition of the patient's privacy and dignity which would encompass the right to die with dignity. This has been premised on the underlying principle to act in accordance with the World Medical Association Declaration of Venice on Terminal Illness.<sup>9</sup> This Declaration looks at issues of care of terminally ill patients by placing the responsibility on the physician to assist the patient "in maintaining an optimal quality of life through controlling symptoms and addressing psychosocial needs enabling the patient to die with dignity and in comfort".<sup>10</sup> The Declaration makes further provisions that physicians should take

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<sup>4</sup> National Health Act 61 of 2003.

<sup>5</sup> Sec 8(1) of the National Health Act 61 of 2003.

<sup>6</sup> National Health Act 61 of 2003.

<sup>7</sup> Ibid.

<sup>8</sup> Norms and Standards Regulations in terms of Section 90 (1) (b) and (c) of the National Health Act 61 of 2003, applicable to certain categories of health establishments. No. R. 109, 18 February 2015.

<sup>9</sup> World Medical Association Declaration of Venice on Terminal Illness. Adopted by the 35<sup>th</sup> World Medical Assembly, Venice, Italy, October 1983 and revised by the 57<sup>th</sup> WMA General Assembly, Pilanesberg, South Africa, October 2006. <https://www.wma.net/policies-post/wma-declaration-of-venice-on-terminal-illness/>. (accessed on 12 January 2018).

<sup>10</sup> Ibid.

steps in encouraging patients to develop written advanced directives. The South African Patient Rights Charter provides for patient's right to refuse treatment; however, it fails to mention advanced directives.<sup>11</sup> The south African legislation does not specifically contain provisions regulating advanced directives or living wills.

In the case of *Clarke v Hurst*<sup>12</sup> the patient had drafted a living will expressing his wish that he not be kept alive through artificial methods. However, the judgment was not based upon recognizing the advanced directive. There was mention of the living will but it did not form the basis of the court reaching its decision. The Health Professions Council of South Africa (HPCSA) guidelines for the Withholding and Withdrawing of Treatment booklet state that "patients should be given the opportunity and encouraged to write advanced directives".<sup>13</sup> As the years progressed more recognition was given to patients and their choice to refuse treatment. Internationally, there has been an increase towards legal recognition of advanced directives. Despite this South Africa has failed to make a leap towards legally recognizing advanced directives namely durable powers of attorney for healthcare.

#### 1.4. Breakdown of Dissertation

The dissertation shall look at advanced directives critically within the South African legal framework. The chapters of this dissertation shall be as follows:

Chapter 1 – The first chapter shall provide a broad overview of the topic and look at the purpose of the dissertation and the background to the topic within South Africa.

Chapter 2 - This chapter will focus on the legal history and development of advanced directives by looking at its inception in the United States and other jurisdictions such as the United Kingdom and Canada.

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<sup>11</sup> Health Professions Council of South Africa. *Guideline for Good Practice in the Health Care Professions National Patients' Rights Charter Booklet 3* (2008).

<sup>12</sup> *Clarke v Hurst* supra.

<sup>13</sup> Health Professions Council of South Africa. *Guideline for the Withholding and Withdrawing of Treatment Booklet 12* (2008).

Chapter 3 - This chapter will examine the ethical considerations surrounding advanced directives within South Africa, which will be discussed and analyzed. The concept of patient autonomy namely prospective patient autonomy shall be focused upon.

Chapter 4 – The fourth chapter will focus on the constitutional and legal principles surrounding advanced directives. Such as section 10 of the Constitution which is the right to dignity. Section 12 which encompasses the right to freedom and security of the person which includes the right to bodily and psychological integrity. Section 15 provides the right to freedom of thought, belief and opinion. Section 7 of the National Health Act<sup>14</sup> makes provision for the importance of patient autonomy.

Chapter 5 – This is the last chapter and it shall conclude the dissertation. The chapter will be divided focusing on advanced directives and surrogate decision making in healthcare respectively. Advantages, as well as recommendations, will be put forth in this concluding chapter.

## 1.5. Terminology and Definitions

For the sake of clarity and to prevent misunderstanding of the terms referred to some of the key terms or words shall be defined below:

### 1.5.1. Advanced Care Planning

Advance care planning is a communication process where people plan for a time when they are unable to make decisions for themselves. It includes reflection, deliberation, and determination of a person's values and wishes or preferences for treatments at the end of life.<sup>15</sup>

### 1.5.2. Advanced Directives

Advanced directives are “instructions given by patients regarding their future treatment should they become incompetent to consent to, or refuse such treatment.”<sup>16</sup> An advanced directive

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<sup>14</sup> Act 61 of 2003.

<sup>15</sup> M Howard, C Bernard, A Tan, M Slaven and D Klein “Advance Care Planning: Let's Start Sooner” (1996) *Canadian Family Physician* 663– 665.

<sup>16</sup> D McQuoid Mason “Advanced Directives and the National Health Act” (2006) 12 *South African Medical Journal* 1236.

allows a person to have the opportunity of making a future medical decision or to elect a proxy to make a medical decision for a patient who is unable to make a decision for themselves.

### 1.5.3. Living Wills

Living wills are advance directives which state “that if a person suffers from an incurable disease or injury that cannot be successfully treated, artificial life-sustaining treatment should be withheld or withdrawn and the patient left to die naturally.”<sup>17</sup> The Living Will is a form of an advanced directive and is written when a person is competent and wishes to make a medical decision for the future. In some instances, and dependent on the wording of the living will and the condition of the patient, such a directive may be interpreted to include a request for a Do-Not-Resuscitate order.<sup>18</sup>

### 1.5.4. Durable Power of Attorney

A durable power of attorney in health care refers to a situation where a person elects someone else to make health care decisions on the patient’s behalf. This is usually seen in circumstances where a patient is mentally incompetent and unable to make a healthcare decision. Patients usually elect a family member to make such a decision on behalf of the patient. This type of power of attorney is referred to as a durable power of attorney since it remains in effect even if the patient becomes mentally incompetent.

### 1.5.5. Do-Not-Resuscitate Order (DNR)

Do-not-resuscitate orders refer to instructions by doctors to health professionals not to resuscitate patients who require cardiopulmonary resuscitations (CPR) in order to save their lives in situations where attempts to apply CPR to them would be futile.<sup>19</sup> Do-not-resuscitate orders are also issued when CPR is against the wishes of the patient or persons legally able to consent on the patient’s behalf.<sup>20</sup>

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<sup>17</sup> I Kennedy and A Grubb *Medical Law: Text with Materials*, 2 ed (1994) 1334-1339.

<sup>18</sup> D McQuoid Mason “Emergency medical treatment and do not resuscitate orders: when can they be used?” (2013) 103(4) *South African Medical Journal* 223.

<sup>19</sup> Ibid.

<sup>20</sup> D McQuoid Mason and M Dada *A—Z Medical Law* (2011) 167.

### 1.5.6. Patient Autonomy

This is one of the most fundamental concepts of medical practice. It was a concept that was initially introduced in the South African case of *Richter and another v Estate Hammann*<sup>21</sup> and further cemented as a legal principle in the case of *Castell v De Greef*.<sup>22</sup> Regarding medical decision-making, the concept of patient autonomy protects the patient's right to self-determination, informed consent and the right to make informed decisions without undue influence from a medical professional.<sup>23</sup> Patient autonomy is an important concept in arguing for the legal validity of advanced directives in health care, with consideration of the patient's wishes.

These principles are based on the notion of respect for the right to bodily and psychological integrity and the right to security and control of one's body, as stated in section 12 of the Constitution of the Republic of South Africa, 1996.<sup>24</sup>

### 1.5.7. Terminal Illness

Terminal illness refers to an illness, injury or other physical or mental condition that in reasonable medical judgment will inevitably cause the untimely death of the patient concerned. And which is causing the patient extreme suffering; or causes a persistent and irreversible vegetative condition with the result that no meaningful existence is possible for the patient.<sup>25</sup>

### 1.5.8. Persistent Vegetative State (PVS)

Persistent vegetative state has been defined as "long term unconsciousness caused by damage to the faculties of the brain that control higher mental functions" (whereby the basic functions such

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<sup>21</sup> *Richter and another v Estate Hammann* 1967 (3) SA 226 (C).

<sup>22</sup> *Castell v De Greef* 1994 (4) SA 408 (C).

<sup>23</sup> H Manyonga, G Howarth, Dinwoodie M, Nisselle P and Whitehouse S "From informed consent to shared decision-making" (2014) 104 *South African Medical Journal* 356.

<sup>24</sup> R Britz and A le Roux-Kemp "Voluntary informed consent and good clinical practice for clinical research in South Africa: ethical and legal perspectives" (2012) 102 *South African Medical Journal* 7.

<sup>25</sup> South African Law Commission. *Proposed End of Life Decisions Act (South Africa Law Commission's Final Draft Bill)*. (1999) 209.

as respiratory and cardiac function are not affected).<sup>26</sup> The patient has no response to stimuli such as pain, movement of the eyes may occur as well as random movements of the limbs.<sup>27</sup>

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<sup>26</sup> D McQuoid Mason and M Dada *A—Z Medical Law* (2011) 32.

<sup>27</sup> *Ibid.*

## **Chapter 2: History and Development of Advanced Directives from an International Law Perspective**

### 2.1. The American Perspective

This chapter shall focus on the inception of advanced directives in the United States, United Kingdom and Canada respectively.

A concept that was initiated in the United States the first living will was proposed by attorney Luis Kutner, where his arguments for legal recognition appeared in the *Indiana Law Journal*.<sup>28</sup> Kutner was a human rights lawyer, in Chicago, who represented the Euthanasia Society of America.<sup>29</sup> He based this concept on the premise of common and constitutional law which provided that “a patient may not be subjected to treatment without his consent.”<sup>30</sup> Kutner made the suggestion that a patient should indicate in writing the extent he or she consents to future treatment. He referred to the document as a “living will,” “a declaration determining the termination of life,” or a “testament permitting death,” among other names.<sup>31</sup> Kutner considered the living will as a “revocable or unconditional trust with the patient’s body being the res, the hospital and doctors as the trustees, and the beneficiary being the patient.”<sup>32</sup> His testamentary and trust paradigm shared the same characteristics as the legal approach that the United States initially adopted in their advanced directive legislation.

In the year 1976 California adopted the first living will statute that created its Directive to Physicians and was termed a living will. This living will aimed at offering an incentive for both the patient and the doctor. The patient was offered a standardized tool that allowed the patient to express his or her wishes with regard to life-sustaining treatment either to withhold or withdraw treatment in the event of unconsciousness or a terminal condition.<sup>33</sup> The doctor, on the other hand, was given statutory immunity when they complied with the patient’s wishes in good faith even though it is presumed that doctors should respect their patient’s wishes.<sup>34</sup>

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<sup>28</sup> L Kutner “Due Process of Euthanasia: The Living Will, A Proposal” (1969) 44 (4) *Indiana Law Journal* 550-551.

<sup>29</sup> *Ibid.*

<sup>30</sup> *Ibid.*

<sup>31</sup> *Ibid.*

<sup>32</sup> *Ibid.*

<sup>33</sup> CP Sabatino “The Evolution of Health Care Advance Planning Law and Policy” (2010) 88(2) *The Milbank Quarterly* 213.

<sup>34</sup> *Ibid.*

The need for legislation covering advanced care directives in the United States was sparked by three cases namely:

The 1976 United States Supreme Court decision of *Re Quinlan*<sup>35</sup> was a case involving a 21-year-old *Karen Quinlan* who had stopped breathing and fell into a coma or persistent vegetative state in 1975.<sup>36</sup> Her condition was said to have been brought upon after she had consumed alcohol and a sedative referred to as Quaalude while on a crash diet. The legal battle began when her parents had requested that her artificial ventilator be removed so that she may be allowed to die. The doctors disinclined to do so claiming such removal would amount to murder. The court in its decision stated that families were adequate decision makers regarding healthcare decisions for patients who were mentally incapacitated.<sup>37</sup> The court further put forth the concept of a prognosis committee later to be what we know as a clinical ethics committee, in an attempt to assist in such causes without judicial measures being sought.<sup>38</sup> In this case, artificial nutrition and hydration were not stopped and *Karen* passed away from pneumonia some 10 years later after the court had granted her artificial ventilation be stopped. The reason behind her artificial nutrition and hydration being continued was based on the fact that her parents had not requested for it to be removed. Hence even after the artificial ventilation was stopped for *Karen*, she continued to breathe unassisted and passed away from the infection. This case highlights an interesting point, in that when a surrogate decision maker makes a decision it has to be specific in respect of the treatment that is being refused. This was evident when the court had decided artificial ventilation could be stopped, yet it made no decision on artificial nutrition and hydration. Later on in this dissertation, a distinction will be drawn between the Canadian case of *Bentley v Maplewood*<sup>39</sup> where one of the issues the court looked at was whether or not nutrition and hydration was included in the definition of healthcare.

In 1990 came the landmark US Supreme Court case of *Cruzan v Director, Missouri Department of Health*.<sup>40</sup> *Nancy Beth Cruzan* was involved in a serious motor vehicle accident in 1976 resulting in her being in a persistent vegetative state. Her parents requested her artificial nutrition and

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<sup>35</sup> *Re Quinlan* 1976 (355) A. 2d 647- NJ: Supreme Court.

<sup>36</sup> *Ibid.*

<sup>37</sup> *Ibid.*

<sup>38</sup> *Ibid.*

<sup>39</sup> *Bentley v Maplewood Seniors Care Society* (2015) BCCA 91.

<sup>40</sup> *Cruzan v. Director, Mo. Dept. of Health* (1990) 497 U.S. 261.

hydration be ceased. The argument, in this case, was about the right of other people in deciding to allow her to die through starvation. After several court hearings, the US Supreme Court ruled that artificial nutrition and hydration be withdrawn. A decision that was based on the right to refuse life-sustaining treatment and the testaments of people who knew *Nancy* and put forward sufficient evidence that *Nancy* would not have wanted to be kept alive in a persistent vegetative state.

The third case involved *Terri Schiavo*<sup>41</sup>, a case which was highly publicized and involved a gruelling legal battle fraught with State and federal politicians all the way to then-President George W. Bush. It was a case that lasted many years from the year 1990 all the way to 2005. In 1990, *Theresa Marie Schiavo* suffered a cardiac arrest one that had caused a hypoxic state resulting in her being in a persistent vegetative state. In 1998 her husband requested that her feeding tube be removed stating that *Terri* would not have wanted to be kept alive in a persistent vegetative state. Unfortunately, no advanced directive regarding healthcare had been written by *Terri* stating her wishes. This case was a good example that illustrated the advantage of having an advanced healthcare directive. Drafting an advanced health care directive can help in avoiding lengthy court battles, the emotional agony and division of decisions that may occur within families with regard to treatment as was witnessed in the aforesaid case.

These three abovementioned US decisions highlighted the importance of an advance health care directive. After the *Quinlan* case, the first laws in support of advanced care directives or living wills were enacted in California namely the Natural Death Act in 1976.<sup>42</sup> The Uniform Rights of the Terminally Ill Act as amended in 1989 sought to regulate advanced directives but the scope was limited to only patients who were suffering from a terminal illness. This was not acceptable considering the narrow scope of the Act that only provides for affected persons whose illness was incurable and irreversible, whose death would occur soon and who was unable to participate in a treatment decision. Over the course of ten years, there was an escalation in living will laws resulting in forty-one States adopting such legislation by the year 1986. As the laws were passed policymakers decided to adopt another legal document known as the durable power of attorney.<sup>43</sup>

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<sup>41</sup> *Schiavo ex rel. Schindler v. Schiavo* (2005) 11<sup>th</sup> Circuit, Court of Appeals.

<sup>42</sup> The Natural Death Act of 1976.

<sup>43</sup> CP Sabatino "Death in the Legislature: Inventing Legal Tools for Autonomy" (1992) 19(2) *New York University Review of Law and Social Change* 39.

The Patient Self-Determination Act<sup>44</sup> was enacted in 1990 and attempted to address the issue of increasing the awareness of advance healthcare directives. This was established by advising all patients of their right to refuse life-sustaining treatment. The legislators realised that such an appointment came with its own downfalls and therefore the States began to develop a special durable power of attorney for health care statutes or alternatively adding proxy provisions to their living will statute.<sup>45</sup> Due to a lack of understanding and use of the advanced directives a new wave of legislation ensued in 1991. New Jersey enacted the first combined statute one that merged a living will and the durable power of attorney also known as a proxy directive into one healthcare directive.<sup>46</sup> As the waves of legislation on advance care directives continued, legislation covering do-not-resuscitate orders and default surrogate healthcare decision-makers were promulgated.<sup>47</sup> In 1993 the Uniform Law Commission promulgated the Uniform Healthcare Decisions Act,<sup>48</sup> which consolidated various state laws that dealt with adult health care and health care powers of attorney. The basic principle of the Act<sup>49</sup> is that a person may make any health care decision which would still remain in force when that person loses capacity. Unfortunately, not all states have adopted this Act,<sup>50</sup> there are six states who have adopted it namely Hawaii, New Mexico, Mississippi, California, Delaware and Maine.<sup>51</sup> The Act<sup>52</sup> attempts to create an easier pathway for a person to make a healthcare decision.

Interestingly, a systematic review was conducted in 2014 on the effectiveness of advanced directives. The outcome of the observational study indicated a decrease in the rate of hospitalization. There was a decrease in deaths in hospitals, a decrease in the use of life-sustaining treatment, and an increased use of hospice and palliative care. This review indicates that advanced directives can have a positive impact on patient care.<sup>53</sup> The effectiveness of an advanced

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<sup>44</sup> The Patient Self Determination Act of 1990.

<sup>45</sup> CP Sabatino "The Evolution of Health Care Advance Planning Law and Policy" (2010) 88(2) *The Milbank Quarterly* 215.

<sup>46</sup> CP Sabatino *Advance Directives and Advance Care Planning: Legal and Policy Issues* (2007).

<sup>47</sup> CP Sabatino "The Evolution of Health Care Advance Planning Law and Policy" (2010) 88(2) *The Milbank Quarterly* 214-215.

<sup>48</sup> Uniform Health-Care Decisions Act of 1993.

<sup>49</sup> Uniform Health-Care Decisions Act of 1993.

<sup>50</sup> Uniform Health-Care Decisions Act of 1993.

<sup>51</sup> The Health Care Decisions Act of 1993.

<sup>52</sup> The Health Care Decisions Act of 1993.

<sup>53</sup> A Brinkman-Stoppelenburg, JA Rietjens and A van der Heide "The effects of advance care planning on end-of-life care: a systematic review" (2014) 28 *Palliative Medicine* 1000.

healthcare directive within the context of South Africa is a point that shall be explored further on in chapter five of this dissertation.

### 2.1.1. Legal Transactional Approach Versus Communications Approach

Initially, American legislation focused on advanced directives with a legal transactional approach which later shifted to a more communications approach.<sup>54</sup> Historically the focus was predominantly on procedural aspects emphasizing standardised forms, which was a way to protect against abuse or an error. However, over the past two decades, there has been a shift towards a more flexible and communication-based approach.<sup>55</sup> These approaches shall be further discussed in the following two paragraphs:

#### Legal Transactional Approach

The legal transactional approach focused on legal steps and procedural requirements setting out what was required for an advanced directive to be legally valid. An advanced directive was treated more along the lines of a contract or conveyance of interest in property.<sup>56</sup> It involved what was known as a substituted judgment which required a surrogate decision maker to make a treatment decision in the same manner that a patient would have decided.<sup>57</sup> The patient's advanced directive was considered as the gold standard in respect of the patient's wishes.

The idea behind the stringent legal formalities was to enforce the seriousness of creating an advanced directive. Especially since a legal representative would usually not help a person in drafting one. Therefore, in order for there to be compliance by health care workers standardised formalities had to be adhered to.<sup>58</sup> This also served as a protection mechanism for the person drafting the advanced directive. It ensured that the advanced directive would be drafted voluntarily and with the full knowledge and acknowledgement of what was said in the document.

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<sup>54</sup> CP Sabatino "The Evolution of Health Care Advance Planning Law and Policy" (2010) 88(2) *The Milbank Quarterly* 214-215.

<sup>55</sup> *Ibid.*

<sup>56</sup> *Ibid.*

<sup>57</sup> *Ibid.*

<sup>58</sup> *Ibid.*

States have required many legal requirements in order to execute an advanced directive, these include the following:<sup>59</sup>

- Standardised statutory form – having a standardised form was considered the safer option. It meant having one form that everyone could draft in accordance to the statute;<sup>60</sup>
- Required disclosures and warnings – some states required that a notice be given to the person executing a healthcare power of attorney;<sup>61</sup>
- Prescribed phrases for authorizing a person’s wishes – specific matters are to be dealt with such as nutrition and hydration - if the person’s wish is to withdraw nutrition and hydration. The state of Ohio, for example, was very specific in that the advanced directive should use the words “terminal condition” or “permanently unconscious state”.<sup>62</sup> A further requirement included the person having to write in bold and in a different font that the attending physician may withhold or withdraw nutrition and hydration;
- Witnessing requirements and restrictions – most states require two adult witnesses for executing an advance directive. The witness cannot be the substitute decision-maker, the treating physician or the physician’s staff. South Carolina has a further restriction on a spouse or anyone who is in charge of the person’s financial state of affairs to sign as a witness.<sup>63</sup> Some states even require the advanced directive to be notarized as well as independently witnessed.<sup>61</sup>
- Limitations on whom may act as a proxy/ substitute decision maker on health care – most states restrict who may be a proxy, especially on the healthcare provider and employees of the healthcare facility. Three states require the proxy to accept the appointment in writing.<sup>64</sup>

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<sup>59</sup> Ibid.

<sup>60</sup> These states included that of Alabama, Kansas, Utah, Oregon.

<sup>61</sup> These states included that of Ohio, Wisconsin, Nevada, Texas.

<sup>62</sup> Ohio’s Revised Code Section 2133.02 requires that the declarant’s declaration shall use either or both of the terms ‘terminal condition’ and ‘permanently unconscious state’ and shall define or otherwise explain those terms in a manner that is substantially consistent with the provisions of the specified code section.

<sup>63</sup> South Carolina’s Code Section 62-5-504 also disqualifies the individual’s spouse and relatives; anyone directly financially responsible for the individual’s medical care or entitled to any portion of the individual’s estate; a beneficiary of a life insurance policy of the individual; and anyone who has a claim against the individual’s estate.

<sup>61</sup> These states are that of Montana, North Carolina and West Virginia.

<sup>64</sup> These states are Michigan, North Dakota and Oregon.

Further procedural requirements are imposed which include a medical diagnosis prerequisite of a terminal condition or permanent unconsciousness. Further limitations involve pregnant women, on a healthcare proxy making a decision on abortion, sterilization, psychosurgery and that involving nutrition and hydration.

The conventionally advanced directive proved to not be as effective. Essentially the lack of effectiveness was as a result of the following:

- less people used the legal tool considering that non-white racial and ethnic groups tend to have less knowledge and less likely to use advance directives.<sup>65</sup> This is an interesting point to look at from a South African perspective. South Africa has a majority of ethnic groups living within the country. This raises the question of how effective would having the ability to draft an advanced directive be, if people within the country do not have much knowledge of what an advanced directive is and how to draft one?
- people found it difficult to determine their healthcare wishes for an unidentified future confronted with unidentifiable illnesses with unpredictable treatments,<sup>66</sup> the prescribed forms for the living will did not provide proper guidance with most people preferring instead to use a surrogate decision maker,<sup>67</sup> the choices that people made had a tendency to change their goals and preferences for care,<sup>68</sup> health care providers tend not to consider an advanced directive because they give preference to other factors such as prognosis, perceived quality of life and wishes of the family.<sup>69</sup>

#### Communications Approach:

In response to the failings of this legal transactional approach, an alternative paradigm was created known as the communications approach.<sup>70</sup> This approach was derived from the more flexible less

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<sup>65</sup> J Kwak and WE Haley "Current Research Findings on End-of Life Decision Making among Racially or Ethnically Diverse Groups" (2005) 45(5) *Gerontologist* 634–641.

<sup>66</sup> A Fagerlin and CE Schneider "Enough: The Failure of the Living Will" (2004) 34(2) *Hastings Center Report* 30–42.

<sup>67</sup> N A Hawkins, PH Ditto, JH Danks and WD Smucker "Micromanaging Death: Process, Preferences, Values, and Goals in End-of-Life Medical Decision Making" (2005) 45(1) *Gerontologist* 107–117.

<sup>68</sup> CP Sabatino "The Evolution of Health Care Advance Planning Law and Policy" (2010) 88(2) *The Milbank Quarterly* 214-215.

<sup>69</sup> SB Hardin and YA Yusufaly "Difficult End-of-Life Treatment Decisions: Do Other Factors Trump Advance Directives?" (2004) 164(14) *Archives of Internal Medicine* 1531–1533.

<sup>70</sup> CP Sabatino "The Evolution of Health Care Advance Planning Law and Policy" (2010) 88(2) *The Milbank Quarterly* 214-215.

legal approach encompassing advance care planning. In addition to legal documentation, communication between patient, family and the physician is done in order to plan not only for healthcare but in regard to finances, family matters, spiritual beliefs and other issues that a person would like to plan for with regard to future health care.<sup>71</sup>

The state of Oregon attempted a protocol using the same concept of advanced care planning. It is known as Physician Orders for Life-Sustaining Treatment, it aims at three elements; first communication between patient and caregiver along with the surrogate decision maker regarding salient end of life care treatment, the patient's wishes is documented by a physician essentially becoming doctor's orders to be kept with the patient's medical records or with the patient that is homebound, thirdly the order is to be kept with the patient at all times of movement hence overcoming the issue of lack of continuity in care decision making and the order is to be recognised by all medical professionals from all facets of the profession. This approach is not an advanced directive but rather builds on the concept of advanced directives. It is a tool that considers the patient's current health state, and healthcare goals and in the absence of an advanced directive a surrogate decision maker makes a decision. Research on the protocol indicated that it was successful in preventing unwanted resuscitations, encouraged discussion of end of life treatment options, and to make the patient's wishes to be known and adhered to.<sup>72</sup> It is submitted that a more communicative approach is needed and even though the advanced directive is the required outcome the process is emphasized on more than the form of the advanced directive. This would be especially more logical when considering the plight of most South Africans. By relying on a more communicative approach it would be easier for people to become more informed and allows for better understanding of advanced directives.

Drafting an advanced directive is not as simple as sitting down and writing what you wish but rather it is a process. One that relies heavily on communication, understanding and acknowledgement of an advanced directive. The communicative approach seen within a South African context, would be an effective way of getting people to draft advanced directives.

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<sup>71</sup> Ibid.

<sup>72</sup> SE Hickman, CP Sabatino, AH Moss and JW Nester "The POLST Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation" (2008) 36(1) *Journal of Law, Medicine and Ethics* 119–140.

## 2.2. The United Kingdom Perspective

In similar contrast to the United States, the United Kingdom found itself facing cases that highlighted the need for legislation concerning advanced directives. The significant cases that created a need for legislative intervention are the following stated below:

### 2.2.1. *Airedale NHS Trust v Bland*<sup>73</sup>

In this case, *Mr. Anthony Bland* was injured in a Hillsborough stadium disaster that left him in a persistent vegetative state in the year 1989. An application was brought by the medical team involved in *Mr Bland's* treatment, asking the court to make an order granting withdrawal of nutrition and hydration and that only treatment that would allow him to die peacefully and in the utmost dignity as possible, be administered to him. The court's decision placed emphasis on patient's autonomy in refusing life-sustaining treatment and considered the possibility of giving such an instruction whilst competent and prior to being incapacitated. In light of this landmark decision, more cases dealt with a patient's capacity to consent or refuse life-sustaining treatment and upheld the same principles as set out in the *Bland* case. It should be noted that this case highlighted that knowledge surrounding the refusal of treatment was not required by the patient. This case was not the first to establish legal recognition of a Living Will but it certainly was the most well-known case whereby the three judges had stated that had there been such a statement it would have been legally binding. This is an interesting point of the case since even though there was no legislation governing an advanced directive the courts were willing to recognise its validity under the common law.<sup>74</sup>

### 2.2.2. *Re C Adult: Refusal of Treatment*<sup>75</sup>

A paranoid schizophrenic patient at a hospital refused to consent to an amputation. The patient was delusional and was being held in custody after having stabbed his partner. In this case, the Honourable judge was of the opinion that, "a person may have capacity to manage his affairs even though he may suffer from schizophrenia."<sup>76</sup> Interestingly, here the court was willing to overlook

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<sup>73</sup> *Airedale NHS Trust v Bland* 1993; 1 All ER 821.

<sup>74</sup> *Ibid.*

<sup>75</sup> *Re C*. 1994; 1 All ER 819.

<sup>76</sup> *Ibid.*

the aspect of the patient being delusional and found that his right to self-determination prevailed even though abiding to the patient's instructions would have led undeniably to his death. This case firmly enforced a patient's right to refusal of treatment and appears to be in favour of the patient autonomy standpoint. It illustrated that a patient does not only have the capacity to refuse treatment but also continuation of care. This is an important advancement in favour of the underlying principle that advanced directives depend upon what is inevitably refusing to have life-sustaining treatment in the future. Maclean submits an alternative argument from a cynic point of view since *C* was a dangerous schizophrenic who had committed murder and offered nothing to society that it did not matter as to whether he lived or died and therefore the choice that would inevitably cause his death was not given relevance.<sup>77</sup>

### 2.2.3. *Re AK*: medical consent<sup>78</sup>

In *Re AK*, this case involved a male 19-year-old who was suffering from a motor neuron disease.<sup>79</sup> Through eye movements, the patient requested that after two weeks of losing his ability to communicate the ventilator should be removed.<sup>80</sup> The court took this as an advance directive verbally and had upheld the advanced directive. The court upheld the refusal of treatment and the removal of the ventilator was allowed. Unfortunately, the decision of the court can be argued against on the basis that the patient's competence was limited taking into account the limited means of communication. Arguably this case does not apply much to patients who are incompetent at the time that a healthcare decision has to be made since this was a contemporaneous decision. However, these above-mentioned cases illustrated advanced directives to refuse life-sustaining treatment being upheld, Maclean argues that this was on the basis of there being a poor quality of life of the patient.<sup>81</sup>

### 2.2.4. *W Healthcare NHS Trust v H* <sup>82</sup>

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<sup>77</sup> AR Maclean "Advance Directives and the Rocky Waters of Anticipatory Decision-Making" (2008) 16 *Medical Law Review* 1-22.

<sup>78</sup> *Re AK* (2001) 1 F.L.R. 129 at 136.

<sup>79</sup> *Ibid.*

<sup>80</sup> *Ibid.*

<sup>81</sup> AR Maclean "Advance Directives and the Rocky Waters of Anticipatory Decision-Making" (2008) 16 *Medical Law Review* 1-22.

<sup>82</sup> *W Healthcare NHS Trust v H* (2005) 1 W.L.R. 834.

A noteworthy case was the Court of appeal judgment in *W Healthcare NHS Trust v H*.<sup>83</sup> The case involved a 59-year-old female patient suffering from a multiple sclerosis disease who needed twenty-four hour care. She lived a minimally cognitive existence even though she was conscious. She had previously stated some ten years ago that she did not want to be kept alive by machines; she had conveyed this to both family and close friends. The court chose to disregard this and did not regard it as an advanced directive. The reasoning provided was that even though she had mentioned machines there was no evidence that she was aware of the dying process due to starvation. Nor had a medical professional informed her on the ramifications of starving to death. Therefore, the court refused to uphold the oral advanced directive given by the patient. What is interesting about the decision is that the court was willing to uphold the advanced directive had she refused treatment of infections.<sup>84</sup> Despite the fact that she had not mentioned anything about treatment regarding infections nor had she discussed the ramifications of infection with a medical profession. This may suggest that the decision was based on the manner of death as opposed to lack of value in the continuation of her life. The case further cements the view that in principle patient autonomy is most important; in practice, it is the sanctity of life and patient's welfare that is important.

#### 2.2.5. The Mental Capacity Act of 2005

The Mental Capacity Act was enacted in 2005, seemingly with the aim to protect patient autonomy from a legislative level. It allows a person to have an influence on how they want to be cared for should that person lack the ability to make a decision in the future. The Act<sup>85</sup> looks at the issues of autonomy and formality, applicability of an advanced directive, continuing validity and applicability of an advance directive, incapacity and revocation, implementation of an advanced directive. Each of these will be discussed below:

- a) Autonomy and formality – the Act<sup>86</sup> proceeds to keep the informality aspect of advanced directives. The exception to the informality is when the directive applies to life sustaining

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<sup>83</sup> Ibid.

<sup>84</sup> AR Maclean "Advance Directives and the Rocky Waters of Anticipatory Decision-Making" (2008) 16 *Medical Law Review* 1-22.

<sup>85</sup> The Mental Capacity Act of 2005.

<sup>86</sup> The Mental Capacity Act of 2005.

treatment, then it must be in writing and executed in the presence of a witness.<sup>87</sup> Additionally, the Act also provides for informal revocations and any alterations.<sup>88</sup> It appears that the legislators attempted to balance flexibility and facilitation against protection of the patient. However, allowing an advanced directive to be revoked by behaviour that is inconsistent leaves a space for interpretation that could lead to physicians and judges justifying an outcome they see as the best.<sup>89</sup> Unfortunately, this is not conducive with the concept of self-determination and the importance of patient autonomy. There may be instances when a person makes a last-minute change of decision, the question then becomes is the formal advanced directive legally binding since a decision made during incapacity does not quite reflect an autonomous decision.<sup>90</sup> Furthermore, an informal revocation or alteration may not be conveyed to the correct medical professional and may not be adhered to or ignored. In an attempt at a compromise, it has been submitted that the responsibility should lie with the person to ensure the advanced directive is updated. Essentially the advanced directive is open to being challenged that said directive is the actual wish of the patient and the Act<sup>91</sup> does not appear to counter this problem.<sup>92</sup> This leads to the next issue, the applicability of advanced directives.

- b) Applicability of Advanced Directives – perhaps one of the more important issues with advanced directives is the difficulty of drafting sufficiently specific advanced directives, considering and anticipating future circumstances especially concerning the withdrawal of treatment. This understandably leaves advanced directives vulnerable to challenge. Section 24 of the Act<sup>93</sup> requires that the directive should state specific treatment yet this may be in lay terms. Even if the circumstances are successfully stated in the directive it is still difficult to say for certain if a directive will be seen as applicable.<sup>94</sup> This is because it

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<sup>87</sup> The Mental Capacity Act of 2005, s25(5), (6).

<sup>88</sup> The Mental Capacity Act of 2005, s24(4), (5).

<sup>89</sup> AR Maclean “Advance Directives and the Rocky Waters of Anticipatory Decision-Making” (2008) 16 *Medical Law Review* 1-22.

<sup>90</sup> *Ibid.*

<sup>91</sup> The Mental Capacity Act of 2005.

<sup>92</sup> *Ibid.*

<sup>93</sup> The Mental Capacity Act of 2005.

<sup>94</sup> D Merritt, W Fox-Grage, M Rothouse, J Lynn, F Cohn and JH Forlini “State Initiatives in End-of-Life Care: Policy Guide for State Legislators” *American Behavioral Scientist* (1998) 28.

would be difficult for patients to specify the circumstances and therefore allows for the opportunity to be challenged by both doctors and judges.

- c) The Continuing Validity and Applicability of an Advanced Directive – in accordance to the English common law there is no time limit on the effectiveness of an advanced directive. Therefore, in principle an advanced directive that was written 20 years ago would still be as effective as one written 2 months ago. However, case law has suggested that the older the advanced directive the more “rigorous and anxious” would be the scrutiny.<sup>95</sup> Instead of invalidating an advanced directive it has been suggested that to ensure patient autonomy is respected the better option would be to leave the responsibility to the patient themselves to ensure that they update their advanced directives. A better suggestion that has been put forward is that the advanced directive be regularly reviewed.<sup>96</sup> Another approach was to impose a time limit on the validity of an advanced directive.<sup>97</sup> Unfortunately, the Act does not make any provision for this instead it appears to be left to the healthcare professional to decide upon the applicability of the advanced directives.
- d) Incapacity and Revocation – if a person wishes to revoke an advanced directive it is required that the person should have capacity to do so. When it comes to the revocation it follows that the onset of incapacity would render an advanced directive irrevocable even if the person subsequently changes his or her mind.<sup>98</sup> It has been suggested that the capacity required would be of a higher degree as opposed to that of a revocation of an advanced directive.<sup>99</sup> The Mental Capacity Act s24 (3) states that a patient may withdraw or revoke an advanced directive as long as the patient has capacity. However, s25 (2) (c) states that an advanced directive will not be valid if the patient does anything else that is inconsistent with the directive.<sup>100</sup> The problem is that this section does not mention capacity, therefore, it can be interpreted to mean that it applies to behaviour even if the person lacks the capacity to revoke the directive.<sup>101</sup>

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<sup>95</sup> *W Healthcare NHS Trust v H* (2005) 1 W.L.R. 834.

<sup>96</sup> Code of Practice for the Mental Capacity Act of 2005.

<sup>97</sup> Joint Committee on Human Rights. *Fourth Report of 2004* (2005) par 4.22.

<sup>98</sup> *HE v A Hospital Trust* (2003) and *E.W.H.C 1017* (2003) 2 F.L.R.

<sup>99</sup> AR Maclean “Advance Directives and the Rocky Waters of Anticipatory Decision-Making” (2008) 16 *Medical Law Review* 1-22.

<sup>100</sup> The Mental Capacity Act of 2005.

<sup>101</sup> AR Maclean “Advance Directives and the Rocky Waters of Anticipatory Decision-Making” (2008) 16 *Medical Law Review* 1-22.

- e) Implementing an Advanced Directive – Under s26 of the Act,<sup>102</sup> health practitioners are provided immunity against deciding if an advanced directive is valid and applicable. This particular provision gives a health practitioner a considerable amount of discretion without this discretion being objectively reasonable.<sup>103</sup>

### 2.3. The Canadian Perspective

During the 1980's Canada did not pass natural death legislation, nevertheless, living wills were recognised under the common law.<sup>104</sup> The development of advanced directives in Canada is as a result of their common law. Even though there is no uniform law on advanced directives there are provincial legislation that attempts to regulate such directives as can be seen in Alberta, Saskatchewan, Manitoba, Newfoundland and Labrador. These provinces have legislation; however, it is not uniform and they differ in the form of the advanced directives as well as the minimum age requirement to draft an advanced directive. The statutes also differ with regards to the form of the advanced directive in each of the provinces.<sup>105</sup> Canada's most recent case was that of *Bentley v Maplewood*<sup>106</sup> and how the court dealt with the advanced directive was very interesting. This case shall be discussed in more detail in Chapter 4 of this dissertation.

#### 2.3.1. The Common Law Approach

By the 1990's the debate between respecting individual rights versus preserving life was more or less resolved. The courts had decided that a competent person has the right to determine what shall be done to their bodies.<sup>107</sup>

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<sup>102</sup> Mental Capacity Act of 2005.

<sup>103</sup> Ibid.

<sup>104</sup> M Brown "The law and practice associated with advance directives in Canada and Australia: Similarities, differences and debates" (2003) 11 *JLM* 59.

<sup>105</sup> E Clough "A Critique of Advance Directives and Advance Directives Legislation"(2006) 11 *Review of Current Law and Law Reform* 16-38.

<sup>106</sup> *Bentley v Maplewood Seniors Care Society* (2015) BCCA 91.

<sup>107</sup> Justice Cardozo's statement in *Schloendo & v. New York Hospital*, 211 N.Y.R. 125 (1914) at 129-130 is often quoted in this regard: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body".

In the Ontario court of appeal case of *Malette v Schulman*<sup>108</sup> a female patient was brought into an emergency room severely injured and unconscious. The patient had carried a card that stated an unwillingness to undergo a blood transfusion due to her religious convictions. The attending doctor, however, had given her a blood transfusion. When the patient woke up and learned that she had been given a blood transfusion, she was mentally and emotionally distraught. This eventually led to the patient laying a charge against the doctor for damages in the battery. The court was of the opinion that the directive should have been followed despite the card not being witnessed or dated. The presiding officer stated "the right to determine what shall be done with one's own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based."<sup>109</sup>

The second important case was also another Court of Appeal matter in Ontario. *Fleming v Reid*<sup>110</sup> involved two psychiatric patients both of whom were competent and both having refused a particular treatment. They had refused treatment with the belief that even if they were to become incompetent their refusal of treatment would be binding. The attending physician resorted to relying on the guardian's decision based on the patient's best interests. The presiding officer Robins J.A stated that the right of a competent person in refusing medical treatment was entrenched in both the common law and the Canadian Charter of Rights and Freedoms.<sup>111</sup> Section 7 of the Canadian Charter of Rights and Freedoms stated that a patient may refuse in advance prospective treatment and it should be honoured even if such treatment would be beneficial or life-saving to the patient and no matter how ill-advised the decision may be.<sup>112</sup> In 1995 the Senate Special Committee on Euthanasia and Assisted Suicide recommended that all jurisdictions should adopt legislation on advanced directives.<sup>113</sup> Apart from the five provinces mentioned who have statute regulating advanced directives, other provinces cover advanced directives through implication. Ontario, Quebec and the Yukon have proxy legislation that allows a proxy to abide by

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<sup>108</sup> *Malette v. Shulman* (1990), 72 O.R. (2d) 417 (C.A.)

<sup>109</sup> *Ibid.*

<sup>110</sup> *Fleming. Reid* (1991) 82 D.L.R. (4<sup>th</sup>) 298, 4 O.R. (3d) 74.

<sup>111</sup> *Ibid.*

<sup>112</sup> Canadian Charter of Rights and Freedoms section 7: "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice".

<sup>113</sup> Senate of Canada *Report of the Special Committee on Euthanasia and Assisted Suicide* (1995) 33.

a patient's previous request regarding his or wishes on treatment.<sup>114</sup> Across Canada, the Living Will or a document called Let Me Decide "if drafted correctly" is generally accepted.

All of these jurisdictions vary in some way or the other with regards to regulating advanced directives and in some aspects, the legislation works well in trying to achieve patient autonomy and respecting patient's wishes. However, these legislations do not always achieve this outcome. Despite this, having legislation regulating advanced directives still helps to lessen issues and provides some sort of guidance when dealing with such matters.

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<sup>114</sup> E Clough "A Critique of Advance Directives and Advance Directives Legislation." (2006) 11 *Review of Current Law and Law Reform* 16-38.

### **Chapter 3: What are the Ethical Considerations Surrounding Advanced Directives?**

The ethics surrounding advanced directives extend from the principles of patient autonomy, well-being and respect for dignity.

#### 3.1. Patient Autonomy

Medical ethics is dependent upon four ethical principles namely that of beneficence, nonmaleficence, patient autonomy and justice. Perhaps the most debated ethical concern in regard to advanced directives lies in that of patient autonomy. Patient autonomy, more specifically prospective patient autonomy forms the ethical basis in favour of advanced directives. Patient autonomy has been stated by Beauchamp and Childress<sup>115</sup> and described as follows:

Personal autonomy is, at a minimum, self-rule that is free from both controlling interferences by others and from limitations, such as inadequate understanding, that prevent meaningful choice. The autonomous individual acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and sets its policies.<sup>116</sup>

From this definition, it can be inferred that the idea behind patient autonomy is having the choice to make decisions and having it adhered to, specifically in this case in making an advanced directive. Nevertheless, patient autonomy has been interpreted in different ways but the underlying concept of self-determination still remains. Ulrich defines autonomy in the following way: A person should be free to perform whatever action he/she wishes, regardless of risks or foolishness as perceived by others, provided it does not impinge on the autonomy of others by intentionally harming them.<sup>117</sup> The ethical principle most linked with advanced directives is that of patient autonomy or self-determination. A mentally competent person has the moral right to make a decision concerning oneself, decisions that are based upon the person's own values, culture and preferences. These decisions involve those that deal with treatment and end of life decisions. The connection between advanced directives and end of life decisions is when the patient refuses future treatment, a treatment that very well may be lifesaving to the patient.

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<sup>115</sup> TL Beauchamp and JF Childress *Principles of Biomedical Ethics* 5 ed (2001).

<sup>116</sup> TL Beauchamp and JF Childress *Principles of Biomedical Ethics* 5 ed (2001) 58.

<sup>117</sup> LP Ulrich *The Patient Self-Determination Act: Meeting the challenges in patient care* 6 ed (1999).

### 3.2. Exercising Prospective Autonomy and its Ethical Concerns in Surrogate Decision Making:

The majority opinion in literature points to the acceptance of an advanced directive having the same legal force as a contemporaneous refusal of treatment.<sup>118</sup> One such opinion is that of Dworkin, who explained the ethical foundations of prospective autonomy in light of refusing treatment.<sup>119</sup> Dworkin's argument is that the societal values of autonomy and dignity require the respect of critical interests of a person. Critical interests are those interests that reflect a person's sense of identity and those interests that give rise to a person's values.<sup>120</sup> It has been suggested that the most important concern of a person refusing medical treatment is a way for that person to preserve his or her dignity when incompetent.<sup>121</sup> Dworkin's argument, therefore, suggests that an advanced directive ought to be adhered to on the basis of preserving a person's critical interest namely how to live and how to die.<sup>122</sup> According to Dworkin,<sup>123</sup> there are two types of interests namely experiential and critical interests, it is the critical interest that is not confined to consciousness. Therefore, a person who is in a coma or a persistent vegetative state could very well still maintain their critical interests.

### 3.3. Advanced Directives and Patient Autonomy

At the heart of individuality is the concept of being able to make a decision about one's wellbeing presently and prospectively. It involves including one's social lifestyle, cultural background, educational background, religious belief and place within society. Preparing an advanced directive is a way for an individual to express their wishes and to have control over their welfare in the event of being incapacitated to make a decision in the future. The incapacitation can be either temporary or permanent. It is a reasonable expectation that the law should have mechanisms in the form of legislation that protects patient autonomy and the self-determination.

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<sup>118</sup> L Jordaan "The Legal Validity of an Advance Refusal of Medical Treatment in South African Law" (2011) *De Jure* 259-273.

<sup>119</sup> Dworkin *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (1993) 200-213.

<sup>120</sup> *Ibid.*

<sup>121</sup> L Jordaan "The Legal Validity of an Advance Refusal of Medical Treatment in South African Law" (2011) *De Jure* 259-273.

<sup>122</sup> *Ibid.*

<sup>123</sup> TP Menzel and B Steinbock "Advanced Directives, Dementia and Physician-assisted Suicide" (2013) *Journal of Law, Medicine and Ethics* 484-502.

One of the mechanisms is to legitimize a durable power of attorney which is a type of advanced directive. A durable power of attorney will allow a trusted person of the patient to make life-sustaining or withdrawal of treatment decisions.

Up until the year 2008, there were no guidelines for doctors to revert to when confronted with a living will. The Health Professional Council of South Africa (HPCSA) took a great step forward in creating ethical guidelines for just this purpose. The underlying principle of these ethical guidelines is that of patient autonomy. An example of this is the ability to refuse treatment even if such refusal would result in death.<sup>124</sup> The HPCSA guidelines make the assumption that the provisions of the National Health Act 61 of 2003, allows patients to give a written mandate to a person or third party to act on their behalf when they are no longer competent to do so.<sup>125</sup> Secondly, the HPCSA suggest that patients should actually be encouraged to appoint through a mandate a person to make decisions on their behalf. It makes provision, more importantly, for patients to be given the opportunity and be encouraged to write advanced directives in certain circumstances such as being in a permanent coma or having a terminal illness.<sup>126</sup> The guidelines further mention the living will and it is interesting to note that the ethical guidelines appear to recognise a living will without there being legislation. Furthermore, the guidelines state that where a patient lacks the capacity to decide, health care practitioners must respect any advanced refusal of treatment. This can be interpreted to mean that an advanced directive could be stated orally or in written form. It is interesting to note that the ethical guidelines clearly recognise advanced directives and that advanced directives are generally accepted and abided by in medical practice. There is a clear discrepancy between the law and the ethical guidelines. There are many arguments against the legal recognition of advance directives. The argument such as the possibility of predicting the future which may lead to a vague advanced directive, refusing treatment may lead to missing out on new medical interventions, inability to change one's mind when a person has become incompetent and the denial of the primacy of individual identity.<sup>127</sup> These are just a few of the arguments against the legal protection of advance directives.

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<sup>124</sup> Health Professions Council of South Africa. *Seeking Patients Informed Consent Booklet 12* (2008) 1.

<sup>125</sup> Health Professions Council of South Africa. *Seeking Patients Informed Consent Booklet 12* (2008) 1-4.

<sup>126</sup> L Jordaan "The Legal Validity of an Advance Refusal of Medical Treatment in South African Law" (2011) *De Jure* 259-273

<sup>127</sup> AR Maclean "Advanced Directives, Future Selves and Decision- Making" (2006) *Medical Law Review* 291-320.

There is little doubt that the future cannot be predicted. Perhaps one of the stronger negative arguments is that an advanced directive has to cover specific circumstances and not merely be a vague statement. When an advanced directive is in vague terms it creates a difficult situation for treating physicians to determine what medical treatment should be excluded. For example, in a situation where an advanced directive might state “I do not want my life to be prolonged when my condition is hopeless and request all treatment to be withheld”, the patient has brain damage and paralyzed yet not considered terminally ill. The same patient acquires pneumonia; it now becomes difficult for a doctor between withholding treatment or treating the pneumonia even though this would be against the patient’s wishes. If put in such a position, most doctors would make a decision based on what is in the best interests of the patient.

Unfortunately, South Africa has not had litigation on advanced directives besides the case of *Clarke v Hurst*<sup>128</sup> as discussed in the first chapter. However, Californian courts had many cases dealing with advanced directives ranging from patients who are in a coma or persistent vegetative state to patients who are seriously ill yet still cognitive.<sup>129</sup> It began with the *Quinlan case*<sup>130</sup> which was followed by the 1983 case of *Barber v Superior Court*.<sup>131</sup> In both these cases, the court allowed for the removal of artificial nutrition and hydration at the request of the families. It is worth noting that in these cases the court had accepted oral advanced directives conveyed through family members. The next cases dealt with advanced directives but involved patients who were seriously ill but were fully cognitive, these cases were on the opposite end of the spectrum from its predecessors. In *Bartling v Superior Court*.<sup>132</sup> a patient who was competent and suffering from emphysema,<sup>133</sup> an abdominal aneurysm<sup>134</sup> and lung cancer requested that his ventilator be removed whilst his physicians objected, the court held that the patient’s wishes should be upheld. In *Bouvia v Superior Court*,<sup>135</sup> the court held that a quadriplegic patient with cerebral palsy should be allowed to request that her artificial nutrition and hydration be withdrawn. Following these

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<sup>128</sup> *Clarke v Hurst No and Others* 1992 (4) SA 630 (D).

<sup>129</sup> Cognitive meaning the person is still connected to thinking or conscious mental processes.

<sup>130</sup> *Re Quinlan* (1976) 355 A. 2d 647- NJ Supreme Court.

<sup>131</sup> *Barber v Superior Court* (1983) 147 Cal App 3d 1006.

<sup>132</sup> *Bartling v Superior Court* (1984) 163 Cal App 3d 186.

<sup>133</sup> Emphysema is a long-term, progressive disease of the lungs that primarily causes shortness of breath due to over- inflation of the alveoli (air sacs in the lung).

<sup>134</sup> An aneurysm is the enlargement of an artery caused by weakness of the arterial wall. Abdominal aneurysm usually occurs in the abdominal aortic artery.

<sup>135</sup> *Bouvia v Superior Court* (1986) 179 Cal.App,3d 1128.

came two cases where the patients were neither comatose nor fully cognitive but in a persistent vegetative state. In *Conservatorship of Drabick*,<sup>136</sup> a patient, who was a motor vehicle accident victim, was in a persistent vegetative state. The court held that a court-appointed conservator could require the physicians to withdraw artificial nutrition and hydration. The case of *Conservatorship of Morrison*<sup>137</sup> the patient was also in a persistent vegetative state, however, the outcome was different. The physicians refused to withdraw artificial nutrition and hydration but they did offer to have the patient transferred to a facility so that withdrawal could be done. The court held that the physicians could refuse based on moral grounds but would be required to transfer the patient as they had offered. The cases had laid the foundation in dealing with surrogate decision makers and different types of patients. Then came the case of *Conservatorship of Wendland*,<sup>138</sup> this case was unprecedented in that it occupied the space between competency and persistent vegetative state.

In *Conservatorship of Wendland*,<sup>139</sup> interestingly the focus was upon the standard of proof that was needed to establish a patient's wishes to the extent known. In Californian law the standard of proof in civil matters is based on a "balance of preponderance" and in criminal matters, the standard is "beyond a reasonable doubt."<sup>140</sup> A further standard of proof which seems to be in the middle of the two is "clear and convincing evidence", which has been the standard for those civil cases that look at fundamental and important rights. *Mr Wendland* had sustained severe brain damage due to a motor vehicle accident; he was minimally conscious but completely dependent on others for basic needs and was unable to communicate. The court held that there was not adequate clear and convincing evidence to suggest the withdrawal of life support. Even though his wife had stated that *Mr Wendland's* wish prior to his accident was not to be kept alive through a life support machine, especially if his condition was hopeless. The issue with this ruling is that the court has essentially concluded that a person's preinjury statements have to be precise with regard to the nature of the condition and the intervention that they wish to be discontinued. It would appear that the Courts are reluctant in allowing the withdrawal of treatment or artificial nutrition and hydration if the person is minimally conscious or with dementia. It has been argued that courts

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<sup>136</sup> *Conservatorship of Drabick* (1988) 200 Cal App 3d 185.

<sup>137</sup> *Conservatorship of Morrison* (1988) 206 Cal App 3d 304, 253 Cal Rptr 530.

<sup>138</sup> *Conservatorship of Wendland* (2001) 26 Cal 4th 555.

<sup>139</sup> *Conservatorship of Wendland* supra.

<sup>140</sup> AB Rich "The Ethics of Surrogate Decision Making" (2002 )176 *West J Med* 127-129.

have a tendency to equate oral statements made by patients prior to being mentally incompetent as an “emotional response to distressing situations.”<sup>132</sup> The court was careful, however, to limit its decision: The clear and convincing evidence standard is justified “only when a conservator seeks to withdraw life-sustaining treatment from a conscious, incompetent patient who has not left legally cognizable instructions for health care or appointed an agent or surrogate for health care decisions.”<sup>141</sup> This decision was based on the premise of clear and convincing evidence and without there being this standard of evidence, withdrawal of life support would be a violation of the person’s constitutional right to life. Essentially the lesson that can be learnt from the *Wendland* decision is that having an advanced directive such as a durable power of attorney for healthcare ensures that a patient’s wishes are adhered to. The lack of an advanced directive may be at the expense of patient autonomy.

#### 3.4. The Concept of Enduring Capacity

The term capacity is an important term in respect of making a decision. The term capacity can be viewed within the medical context and within the legal context. In the legal context, capacity refers to a person’s ability to perform a specific juristic act.<sup>142</sup> From a medical perspective, capacity relates to a clinical evaluation of an individual’s functional ability to make autonomous decisions.<sup>143</sup> There is a link between the capacity to make decisions and autonomy. The basic idea behind making an advanced directive is having a decision to be made prospectively and not have it revoked on the basis of incapacity. Currently, South Africa does not have a statute that regulates this concept and it is with this in mind that a durable power of attorney is being advocated for in this dissertation.

#### 3.5. Conclusion

If one were to accept the ethics of a competent person’s contemporaneous decision regarding withdrawal of treatment, then a person’s prospective decision should also be accepted. Ethics is basically our moral insights which form the standard of ethically acceptable conduct.<sup>144</sup> An apt

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<sup>141</sup> *Conservatorship of Wendland supra.*

<sup>142</sup> South African Law Commission *Assisted Decision Making: Adults with impaired Decision – Making Capacity* (2004).

<sup>143</sup> *Ibid.*

<sup>144</sup> WA Landman “End-of –Life decisions, ethics and the law: A case for statutory legal clarity and reform in South Africa” (2012) *Ethics Institute of South Africa* 17-19.

example is that of slavery, slavery was considered as an acceptable norm in society nowadays it is considered unthinkable in our current legal dispensation. The ever-evolving position of women globally is another prime example of how law and ethics are entwined and constantly evolving.

## **Chapter 4: A Legal Perspective of Advanced Directives Internationally and within South Africa**

### 4.1. Introduction

There has been a shift in thinking surrounding incompetent people, previously they used to be considered as simply dependent on others. The new wave of thinking is in line with respecting patient autonomy and dignity irrespective of a person being competent or incompetent. The focus has been more rights-based as opposed to a needs-based approach. These rights flow from International Guidelines, our Constitution, certain law and policy developments and sociological factors within South Africa. A legal approach towards advanced directives will be discussed in this chapter beginning with some international guidelines and looking at both international and South African case law.

### 4.2. International Guidelines

The World Medical Association Declaration of Venice on Terminal Illness<sup>145</sup> was one of the initial legal instruments that focused on decisions surrounding terminally ill persons. This Declaration looks at issues of care of terminally ill patients by placing the responsibility on the physician to assist the patient “in maintaining an optimal quality of life through controlling symptoms and addressing psychosocial needs enabling the patient to die with dignity and in comfort”.<sup>146</sup> The Declaration makes further provisions that physicians should take steps in encouraging patients to develop written advanced directives.

The new trend in comparable jurisdictions have now made provision for durable powers of Attorney, initially, living wills were used however many issues arose leading to the legislators introducing the Enduring Power of Attorney. Essentially this type of advanced directive allows for the patient’s wishes and for the input of a surrogate who in all likelihood will be aware of the patient’s beliefs and values. Surrogate decision makers have two main responsibilities in other

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<sup>145</sup> World Medical Association Declaration of Venice on Terminal Illness. Adopted by the 35<sup>th</sup> World Medical Assembly, Venice, Italy, October 1983 and revised by the 57<sup>th</sup> WMA General Assembly, Pilanesberg, South Africa, October 2006. <https://www.wma.net/policies-post/wma-declaration-of-venice-on-terminal-illness/>, (accessed on 12 January 2018)

<sup>146</sup> Ibid.

jurisdictions, firstly to exercise rights on behalf of the mentally incompetent or incapacitated patient and secondly to protect the rights and interests of the patient.<sup>147</sup> Legislation has attempted to achieve a balance between autonomy and paternalism. This is quite important because it creates a balance that strives towards the best interest of the patient. Apart from balancing the rights of the patient, all of the jurisdictions have attempted either minimally or to a greater extent to balance procedural considerations and welfare considerations. Generally, priority is given to family members or next of kin with regard to surrogate decision making. It should be borne in mind, however, that even though other jurisdictions such as the United States, Canada, etc. have managed to create this legal reform, developing countries do not have the same circumstances. Legal reform has to be achieved with specificity in accordance with a developing country's particular needs and vulnerabilities.

The reality of developing countries is quite different from first world countries and therefore a more African perspective is required especially for South Africa. In the end, it is the prevailing circumstances of a country that determines how that country should deal with regulating advanced directives. African countries differ a great deal from Western countries with regard to beliefs, culture, sociological perspectives and economics. In a recent study conducted in Kenya, it was revealed that within the African culture the discussion of death in itself is seen as a taboo.<sup>148</sup> It is not uncommon for most people living in Africa to have minimal knowledge of advanced directives. This was evident in the study that was conducted in 2017, which involved two hundred and sixteen (216) patients. Out of the two hundred and sixteen (216) patients who were terminally ill, only eighty-nine (89) patients had advanced directives. The rest of the one hundred and twenty-seven (127) patients had no advanced directives drafted. The results of the study can be attributed to most people not having enough knowledge about advanced directives. Those patients who had advanced directives were usually people who had had the opportunity of discussing it with their physicians.<sup>149</sup> It can be concluded that a communicative approach plays a pivotal role in the drafting and advanced directives. This is relevant within a South African context considering socio-economic backgrounds of the majority of South Africans.

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<sup>147</sup> South African Law Commission *Assisted Decision Making: Adults with impaired Decision – Making Capacity* (2004).

<sup>148</sup> S Omondi, J Weru, AJ Shaikh and G Yonga "Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya" (2017) 16 *BMC Palliative Care* 9-10.

<sup>149</sup> *Ibid.*

### 4.3. Constitutional Principles Applicable to Advanced Directives

With the advent of the South African Constitution<sup>150</sup> in 1996, rights such as dignity, equality and freedom have been entrenched in our country. This constitutional protection is afforded to everyone in South Africa including those who are competent and incompetent alike.<sup>151</sup> This is firmly entrenched in Section 9 of the Constitution which is the equality clause. It has been argued that the right to equality is linked with the right to dignity. The Constitution affords the right of inherent dignity to everyone, a right that ought to be respected and protected. In *Hoffmann v South African Airways*<sup>152</sup>, the Honourable Ngcobo J set out the link between these rights and the importance of the link.

“At the heart of the prohibition of unfair discrimination is the recognition that under our Constitution all human beings, regardless of their position in society, must be accorded equal dignity. That dignity is impaired when a person is unfairly discriminated against. The determining factor regarding the unfairness of the discrimination is its impact on the person discriminated against. Relevant considerations in this regard include the position of the victim of the discrimination in society, the purpose sought to be achieved by the discrimination, the extent to which the rights or interests of the victims of the discrimination have been affected, and whether the discrimination has impaired the human dignity of the victim.”<sup>153</sup>

Not respecting what a patient chooses in respect of treatment is a type of discrimination based on incompetence or disability. When a competent person makes a decision and then is incapacitated subsequently that person is still the same person and therefore should retain that identity through the advanced directive.

Section 10 of the Constitution involves the right to dignity which is afforded to all people within South Africa. The right to dignity is not only recognised it has to be protected in the true spirit of

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<sup>150</sup> The Constitution of the Republic of South Africa, 1996.

<sup>151</sup> The Constitution of South Africa Act 108 of 1996, Chapter 2.

<sup>152</sup> *Hoffman v South African Airways* (2000) 12 BLLR 1365 (CC).

<sup>153</sup> *Hoffman v South African Airways* supra.

the Constitution. In respect of incompetent people with advanced directives, their inherent dignity is being portrayed through a substitute decision maker or their advanced directive document that states their wishes or belief.

The National Health Act<sup>154</sup> mentions that family members or others may make health care decisions as substitute decision makers. Although this is a step in the right direction, it does raise concerns when medical practitioners are requested to withdraw or withhold treatment as directed by a substitute decision maker. Importance should be given to how a person chooses to live. A person living a life they value as dignified should be focused upon especially in respect of healthcare decisions and the refusal of life-sustaining treatment. Many incompetent patients are simply confined to bed, cannot move or speak, cannot use the basic amenities of life and completely confined to relying on someone else for everything from eating to defecating. It is doubtful anyone would classify this as being a fulfilled and dignified way of living. It is submitted that human dignity ought to be protected right up to and including the moment of death. Accordingly, even a person who is not competent ought to retain the right to dignity more specifically through a durable power of attorney.

Section 11 of the Bill of Rights states that “everyone has a right to life”.<sup>155</sup> The right to life was a concept which was substantially dealt with in the Constitutional case of *S v Makwanyane*.<sup>156</sup> From this decision, it can be further concluded that the right to life has a more broad and wider meaning as opposed to a narrow approach.<sup>157</sup> This point was aptly stated in the remarks of O’Regan J in *S v Makwanyane*:<sup>158</sup>

But the right to life was included in the Constitution not simply to enshrine the right to existence. It is not life as mere organic matter that the Constitution cherishes but the right to human life; the right to live as a human being, to be part of a broader community, to share in the experience of humanity.

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<sup>154</sup> The National Health Act 61 of 2003; s7(1).

<sup>155</sup> The Constitution of the Republic of South Africa Act, 1996.

<sup>156</sup> *S v Makwanyane* 1995 (3) SA 391 (CC), 1995 (6) BCLR 665 (CC) para 326.

<sup>157</sup> *Ibid.*

<sup>158</sup> *Ibid.*

In her concurring opinion, O'Regan J managed to capture the essence of the right to life. Living cannot be seen simply from a mechanical perspective. To live is much more than existing in a visceral sense. It has been argued that human life is more than a simple continuation of breathing<sup>159</sup> this is certainly true, living means to experience life with emotions, understanding and appreciation. Therefore, an extension to this right to life could include us as individuals having a say in the type of life we wish to lead. Legislation that makes allowance for a person to make an autonomous decision and which promotes the adherence to such a decision is in line with an open and democratic society. Professor Geoffrey Falkson has correctly said, "The accent should be on the sacredness of the quality of life, rather than the sacredness of life per se."<sup>160</sup> Technically speaking the Constitution<sup>161</sup> provides for the right to live but does not impose a duty to live.

Section 12(2) of the Constitution<sup>162</sup> affords the right to bodily and psychological integrity. It is the idea of integrity that is especially relevant with regard to self-determination and autonomy. Section 12 of the Constitution<sup>163</sup> protects the right of self-determination with regard to one's body against interference from others and the State. The right to self-determination directly stems from patient autonomy.<sup>164</sup> Even though these rights are stated in the Constitution<sup>165</sup> it should be borne in mind that these rights are not absolute and subject to Section 36 of the Constitution.<sup>166</sup> This section is the limitation clause, which provides that rights may be limited as long as the limitation is reasonable and justifiable.<sup>167</sup> The more severe the limitation the more the justification has to be provided for that limitation. A legal issue is made when self-determination or patient autonomy has to be limited when the choices that are made need legal intervention. For example, when a person has become mentally incompetent, the law may be required to intervene to act in the best interests of that now incompetent person. Recognizing patient autonomy as a constitutional right

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<sup>159</sup> South African Law Commission *Euthanasia and the Artificial Preservation of Life* (1998).

<sup>160</sup> *Ibid.*

<sup>161</sup> The Constitution of the Republic of South Africa Act, 1996.

<sup>162</sup> The Constitution of the Republic of South Africa Act, 1996.

<sup>163</sup> *Ibid.*

<sup>164</sup> South African Law Commission *Assisted Decision Making: Adults with impaired Decision – Making Capacity* (2004).

<sup>165</sup> The Constitution of the Republic of South Africa Act, 1996.

<sup>166</sup> *Ibid.*

<sup>167</sup> According to sec 36(1) of the Constitution, the rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including the nature of the right; the importance of the purpose of the limitation; the nature and extent of the limitation; the relation between the limitation and its purpose; and less restrictive means to achieve the purpose.

means that the limitation or interference in this right has to be as minimal as possible. South African legal experts have expressed a unanimous opinion that in cases when there is diminished capacity or absence of autonomy the Court or a legally appointed substitute decision maker would be required to substitute its own decision for the autonomous judgment that would have been made by the incapacitated person.<sup>168</sup> Essentially the right to self-determination demands that the decision gives primary weight to patient autonomy.<sup>169</sup> The respect for patient autonomy is demonstrated in the HPCSA's General Ethical Guidelines, the relevant parts being the medical practitioner's obligation to respect a patient's right to self-determination.<sup>170</sup> As the right to physical integrity which includes the ability to make an autonomous decision is enshrined in the Bill of rights, there is a general legal obligation on medical practitioners to respect this right.<sup>156</sup> The further implication being that any intervention from the law into people's lives should be as minimal as possible.

Section 14 of the Constitution<sup>171</sup> encompasses the right of privacy. In *Bernstein v Bester*<sup>172</sup> a matter that was before the Constitutional Court where Judge Ackerman discussed this right and stated:

"The scope of privacy has been closely related to the concept of identity and it has been stated that 'rights like the right to privacy, are not based on a notion of the unencumbered self, but on the notion of what is necessary to have one's own autonomous identity... In the context of privacy, this would mean that it is only the inner sanctum of a person, such as his or her family life, sexual preference and home environment, which is shielded from erosion by conflicting rights of the community.'"<sup>173</sup>

The relevance of this judgment is that it speaks to the essence of having the right to privacy as an individual. It embraces patient autonomy and inner sanctum which means that a person has a choice not to live a life filled with pain and suffering.<sup>174</sup> Arguably, this could mean that a person may choose to have an advanced directive or to have a surrogate decision maker, and make a choice of withdrawal of treatment. If advanced directives were legislated and regulated

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<sup>168</sup> South African Law Commission *Assisted Decision Making: Adults with impaired Decision – Making Capacity* (2004).

<sup>169</sup> *Ibid.*

<sup>170</sup> Health Professions Council of South Africa *Guidelines for good practice in the health care professions Booklet 1* (2008) 2.

<sup>171</sup> The Constitution of the Republic of South Africa Act, 1996.

<sup>172</sup> *Bernstein v Bester* 1996 (4) BCLR 449 (CC).

<sup>173</sup> *Bernstein v Bester* supra.

<sup>174</sup> South African Law Commission *Euthanasia and the Artificial Preservation of Life* (1998).

accordingly it would allow for a person's right to privacy being protected. Of course, not only the right to privacy would be protected but so would the other accompanying rights such as the right to dignity, right to life and the right to freedom of choice would be protected. This would be bearing in mind the limitation clause i.e. section 36 of the Constitution.<sup>175</sup>

#### 4.4. Recent Case Law Involving an Advanced Directive

Within South Africa besides that of *Clarke v Hurst*,<sup>176</sup> have not been any advanced directive related cases appearing before the court. This may be disadvantageous in the sense that the common law has not been developed in South Africa regarding advanced directives. Unfortunately, even further is that in *Clarke v Hurst*<sup>177</sup> the Court did not validate the living will of the patient. The essence of the judgment was that the discontinuance of medical treatment in these circumstances would not be considered unlawful. The reasoning behind the judgement was also not based on the advanced directive. Therefore, even though it is an important case, foreign case law has to be considered in order to ascertain how to deal with advanced directives from a court's perspective. Foreign case law will be helpful and can be used as a reference point, however; it will not be seen as binding within South Africa. Currently, there is no reported judgment directly ruled on with regard to advanced directives.

##### 4.4.1. *Bentley v Maplewood Seniors Care Society*

One of the most important decisions dealing with advanced directives is the Canadian case of *Bentley v. Maplewood Seniors Care Society*<sup>178</sup> which was first before the British Supreme Court and then before the British Columbia Supreme Court of Appeal.

The case involved one *Margot Bentley* who was an 83-year-old woman who suffered from Alzheimer's disease. During her earlier and healthier years *Margot Bentley*, who was a nurse, expressed that after witnessing patients in a persistent vegetative state due to Alzheimer's disease, she would not want to be kept in the same way. She went even further by drafting and

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<sup>175</sup> The Constitution of the Republic of South Africa Act, 1996.

<sup>176</sup> *Clarke v Hurst* 1992 (4) SA 630 (D).

<sup>177</sup> *Clarke v Hurst* supra.

<sup>178</sup> *Bentley v Maplewood Seniors Care Society* (2014) BCSC 165 and *Bentley v Maplewood Seniors Care Society* (2015) BCCA 91.

signing an advanced directive stating family members as proxies to make healthcare decisions on her behalf, essentially an enduring power of attorney.

The court a quo<sup>179</sup> had to deal with a number of issues however only the relevant ones will be discussed further:

- Whether *Mrs Bentley* was currently capable of making the decision to accept nourishment and assistance with feeding?

The Honourable Judge Greyell ruled that *Mrs Bentley* was indeed capable of making the decision to accept nutrition and was providing her consent through her behaviour when she accepts nutrition and liquids.<sup>164</sup> This was based on various factors namely the petitioners, in this case, had failed to show that *Mrs Bentley* was not capable of making a decision involving eating and drinking, the judge favoured the one expert's opinion over the other's. The BC Court of Appeal agreed with Judge Greyell and reaffirmed that what was required of the petitioners was to counter the presumption that *Mrs Bentley* was capable of giving consent.<sup>180</sup>

- Does assistance with feeding fall within the definition of healthcare or personal care?

The judge stated that the British Columbia's Health Care Consent and Care Facility Admission Act (HCCCFA Act) does not define oral nutrition or hydration under health care.<sup>181</sup> The Judge further looked at the Representation Agreement Act which included the term diet under the definition of personal care, along with shelter, dress, participation in activities, licenses and permits.<sup>182</sup> The reasoning for the decision was since a representation agreement can authorize decisions about personal care as well as healthcare and since nutrition, assistance with eating and meal planning fell under community care, the inference made was eating and drinking must be personal care matters and not healthcare.<sup>183</sup>

- Could *Mrs Bentley's* statement of wishes be considered as an advanced directive?

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<sup>179</sup> *Bentley v Maplewood Seniors Care Society* (2014) BCSC 165.

<sup>164</sup> *Bentley v Maplewood Seniors Care Society* supra.

<sup>180</sup> *Bentley v Maplewood Seniors Care Society* (2015) BCCA 91.

<sup>181</sup> *Bentley v Maplewood Seniors Care Society* (2014) BCSC 165.

<sup>182</sup> *Bentley v Maplewood Seniors Care Society* (2014) BCSC 165.

<sup>183</sup> *Bentley v Maplewood Seniors Care Society* supra.

Advanced directives need to be specifically worded in order to be recognised as one. In this case *Mrs Bentley* indicated that her husband or daughter could make a decision on her behalf. In order for this statement to be recognised as an advanced directive, the Court was of the opinion that no one should be selected as a temporary decision maker.<sup>184</sup> In this case, *Mrs Bentley* indicated surrogate decision makers and therefore, it was not recognised as an advanced directive.

- If *Mrs Bentley* is unable to make a decision on nourishment, who has the authority to make the decision?

There is a representative agreement that exists under the Representation Act in British Columbia.<sup>185</sup> Under this Act<sup>186</sup> a person may nominate a substitute decision maker, it sets out the requirements for the agreement to come into effect. If *Mrs Bentley* had filled out the RA9 form under this act she could have nominated her husband or daughter to make a decision on her behalf. The RA9 form allows a representative to even refuse healthcare according to the person's wishes, even if this would lead to that person's eventual death. The court refused to consider the statement of wishes as an advanced directive. Even if it did consider the statement it would not have made a difference in this case as advanced directives only apply to healthcare and in this case, the issue was personal care.<sup>187</sup>

The lesson that can be appreciated from this case is that South Africa would have to ensure that when recognising advanced directives, it should be applicable to all types of medical care including personal care like that of feeding. In so far as definitions of healthcare is concerned our current legislation does not specifically define the term "healthcare" and our courts may very well face the same issue of the British Columbian Court. Another point coming from the *Bentley v Maplewood*<sup>188</sup> case is how specific an advanced directive should be for the court to consider it in its decision. Interestingly, the United Kingdom's legislation has a similar approach with regard to the specificity of an advanced directive. The United States Supreme Court decision *Re Quinlan*<sup>189</sup>, unlike the

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<sup>184</sup> *Bentley v Maplewood Seniors Care Society supra*.

<sup>185</sup> The Representation Agreement Act of 1996.

<sup>186</sup> *Ibid*.

<sup>187</sup> *Ibid*.

<sup>188</sup> *Ibid*.

<sup>189</sup> *Re Quinlan supra*.

Bentley case, didn't look at the definition of nutrition and hydration and if it had it is questionable whether the court would have come to a similar decision as that of the Canadian case

The reality of most South Africans is that to predict precisely a consequence may very well be an almost impossible task. Medical knowledge in itself is confusing and the ordinary South African may not even be literate, this could potentially create a lot of reluctance in drafting an advanced directive in the first instance. However, perhaps a better option would be to introduce a procedure similar to that of HIV testing counselling, whereby people are counselled and informed by health care workers on advanced directives and how it should be drafted.

Substitute decision-makers may be tasked with deciding upon treatment with regard to pain relief and distress apart from just life-sustaining treatment. The South Africa Law Commission Report, in its draft legislation, looked at this aspect but from a health care practitioner's perspective. The report suggested that a health practitioner may increase the dosage of pain medication even if that would lead to a patient's death as long as certain formalities were abided by, like a prescribed record keeping.<sup>190</sup> The conclusion that can be drawn from this being that comfort care can be indemnified from civil and criminal liability as long as a responsible clinical judgment has been made. In a similar stance, if a substitute decision maker were to make a decision that is carefully considered and in the best interest of the patient, then there should be no legal liability on the part of the health care practitioner. This should also be the case in withdrawal or withholding life-sustaining treatment which could potentially lead to the patient's death.

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<sup>190</sup> South African Law Commission *Euthanasia and the artificial preservation of life* (1998).

## **Chapter 5: Conclusion and Recommendations**

### 5.1. Introduction

This chapter seeks to offer a conclusion to this dissertation, hopefully having asserted the need and demand for legislative regulation of advanced directives. It should be noted that the conclusion will be divided into two parts, one that refers to advanced directives drafted by a competent person who subsequently becomes incompetent. The second part of the conclusion will focus on surrogate decision making, whereby a competent person makes an advanced directive and appoints a third person to act as a surrogate decision-maker regarding healthcare or withdrawal of treatment. Throughout this dissertation, advanced directives and durable power of attorney has been mentioned and at times interchangeably, therefore, an explanation has been provided to create clarity on the terms.

### 5.2. Advanced Directives

As previously mentioned an advanced directive are instructions given by patients regarding their future treatment should they become incompetent to consent to, or refuse such treatment.<sup>191</sup> An advanced directive allows a person to have the opportunity of making a future medical decision or by electing a proxy to make a medical decision for a patient who is unable to make a decision for themselves. It is worth noting that a durable power of attorney is a form of an advanced directive and hence it has been referred to interchangeably throughout the dissertation. The only difference between these is that in one the person's wishes are stated and with a durable power of attorney it is the substitute decision maker who states what the person's wishes are regarding treatment or withdrawal thereof.

Legislation should state that a competent person has the right to contemporaneously make a decision regarding prospective life-sustaining treatment.<sup>192</sup> It has been argued that this would at least clear our case law's recognition of a patient's right to refuse life - saving treatment.<sup>193</sup> Artificial nutrition and hydration ought to be recognised as medical treatment, which would clear

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<sup>191</sup> D McQuoid Mason "Advanced Directives and the National Health Act" (2006) 12 *South African Medical Journal* 1236.

<sup>192</sup> WA Landman "End-of -Life decisions, ethics and the law: A case for statutory legal clarity and reform in South Africa" (2012) *Ethics Institute of South Africa* 17-19.

<sup>193</sup> *Ibid.*

any ambiguity. Naturally, when this is withdrawn it should be accompanied by comfort care treatment and pain management treatment.

Advanced directives are legally recognised in international law as discussed, in South Africa, the National Health Act<sup>194</sup> does identify advanced directives but fails to properly define terms like Living Will and Durable Power of Attorney.

### 5.2.1. Advantages and Recommendations regarding Advanced Directives

- One of the main advantages of legislating advanced directives means that people who become incompetent can have their rights protected legally. Legislation can provide clarity on matters such as temporary incapacity, persistent vegetative state patients and withdrawal of treatment.
- The South African courts are currently overflowing with matters to appear before a Magistrate or Judge. Therefore, by creating a legal guideline for doctors and patients, it prevents the unnecessary step of appearing in court and thus overloading the courts.
- The state of the health care system is under great financial stress and resources are extremely limited. The hospitals cannot accommodate all patients, as there are overcrowding and downgrading or shutting down of hospitals due to financial constraints. Care of the terminally ill and those in persistent vegetative state is very expensive. It appears more logical not to expend the already scarce health care resources on these patients.

### 5.3. Durable Power of Attorney

Currently, South Africa does not have any law relating to a durable power of attorney. In our law, a power of attorney is a declaration whereby one person delegates the power to make decisions on behalf of that authorizer.<sup>195</sup> This is not the only manner in which a person may be authorized to act on behalf of another person, for example when a court appoints a curator to a person or the property of another person.<sup>196</sup> Unfortunately, our law does not make provision for a durable power of attorney for healthcare. A durable power of attorney is a special type that manages to

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<sup>194</sup> The National Health Act 61 of 2003.

<sup>195</sup> De Wet *Law of South Africa* Vol 1 par 116.

<sup>196</sup> Ibid.

focus on the persons wishes even when that person has become incompetent and unable to make a choice regarding health care. A substitute decision maker can, therefore, act on behalf of the now incompetent person.

Many are under the impression that having an ordinary power of attorney confers the right to make decisions for another who has become incapacitated. This is false; a power of attorney ordinarily does not continue to be valid, since a power of attorney ends when a person's capacity ends. This is precisely the reason why a durable power of attorney should be introduced into our law. Another pertinent issue regarding advanced directives is that patients assume that in practice their advanced directives will be adhered to by the doctors. However, the reality is that an advanced directive has to be specific and if it is not specific to the patient's circumstances then it is most likely that the advanced directive will not be taken into consideration.<sup>197</sup> It is common practice that when decisions need to be made regarding incapacitated patients, it is usually the family members who make decisions even though they have no legal basis upon which they may act. This has the potential to expose these family members to personal liability.

Our law currently deals only with decision making incapacity and recognizes a curator to handle the affairs of the incapacitated person or to have legal standing to take up matters in court. Similar to a curator, a surrogate decision-maker, if recognised, would be able to make health care decisions on behalf of a patient without that decision being overridden by family members or health care professionals. In so far as the surrogate decision-maker acts in the best interest of the patient and in line with the patient's wishes. It might be a good idea to have a monitoring system like that in British Columbian Representative Agreement Act, whereby there is an appointed monitor who oversees the decisions of the surrogate decision maker and that the best interests of the patient are being taken into account.

#### 5.3.1. Advantages of a Durable Power of Attorney

A primarily significant advantage is that essentially it is the patient who is making a decision about healthcare even if the decision is not contemporaneous.

- The introduction of statutory substitute decision making will solve issues that involve the so-called grey areas of temporary incapacity.

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<sup>197</sup> R Ingle "End-of-life decisions (Letters)" (2008) 98(5) *South African Medical Journal* 332.

- The best interests of incompetent persons will be focused upon especially if legislation recognizes and enforces this right.
- “Proper safeguards should be built into the process to protect the interests of the principal. These should include execution safeguards; triggering event safeguards (i.e. safeguards conclusively establishing or indicating whether the agent can continue to validly act under an enduring power of attorney or start validly acting under a conditional power of attorney); and supervisory safeguards.”<sup>198</sup>
- When a substitute-decision maker is making healthcare decisions, it should be on the basis of appropriate standards in the circumstances such as:
  - Based on what the decision maker knows about the patient, an inference based on what the patient would have actually wanted;
  - By placing oneself in the position of the patient and deducing what the patient would have probably wanted in the circumstances; and
  - By inevitably choosing the option that would objectively reap the highest benefit for the patient.<sup>199</sup>
  - In cases where there is no advanced directive but a substitute decision maker, the same principles of the appropriate standard of care would apply.<sup>200</sup>

Substitute - decision-makers ultimately stand in for a patient when the patient has become incompetent. This type of power of attorney can either be one where the patient has given the substitute decision maker specific instructions or one where the patient has basically left the decision up to the substitute. The decision maker is then dependent on the situation and circumstances surrounding a patient’s condition. When deciding if life-sustaining treatment should be withheld or withdrawn, what needs to be determined is the appropriateness of the treatment.<sup>201</sup> The goal of the treatment should be to the benefit of the patient. If there is no life possible even if vital functions are sustained artificially, there is no point in continuing treatment. Essentially merely having a biological life with no prospect of conscious life, is a treatment that has

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<sup>198</sup> South African Law Commission *Assisted Decision Making: Adults with impaired Decision – Making Capacity* (2004).

<sup>199</sup> WA Landman “End-of –Life decisions, ethics and the law: A case for statutory legal clarity and reform in South Africa” (2012) *Ethics Institute of South Africa* 17-19.

<sup>200</sup> *Ibid.*

<sup>201</sup> *Ibid.*

an inappropriate goal. In a persistent vegetative state patient, for example, withholding antibiotics for a life-threatening infection would be ethically justifiable since meaningful life or recovery to a conscious state would be unattainable and impossible. This would still be ethically justifiable if such withholding of treatment would inevitably lead to the patient's death. Drawing from the *Clark v Hurst*<sup>202</sup> decision, if the discontinuance of treatment would be wrongful based on the legal convictions of our society and whether it would be reasonable within the circumstances of the patient's illness, should be the test in deciding lawfulness of the decision. The other justification which is extrinsically based is that within South Africa we cannot afford futile treatment on any patient. South Africa has barely enough resources to treat patients and treating a patient with a very bad prognosis would be a waste of already scarce medical resources that we cannot afford.

By formally introducing this concept it would not only create legal certainty, which in any event is being adhered to in practice anyway. It will increase the awareness of a durable power of attorney as it is not generally known that it ends with a person's capacity. When introduced formally the concept will be properly regulated and incapacitated person's wishes will still be upheld and protected.

From a practical perspective, people will need to be educated on advanced directives and the different types of advanced directives, how to draft an advanced directive, availability in acute care settings and long term care.<sup>203</sup>

#### 5.4. Conclusion

Legal clarity will assist in providing guidance for substitute decision makers and healthcare practitioners, protection of a patient's wishes and respect for patient autonomy, protection for healthcare practitioners and decision-makers who act in accordance to lawful medical practice. It will provide peace of mind for family members knowing that they don't need to become entangled in stressful and tedious legal litigation. Health care practitioners will not fear litigation and issues in respect of advanced directives with or without substitute – decision makers.

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<sup>202</sup> Clarke v Hurst No and Others 1992 (4) SA 630 (D).

<sup>203</sup> WA Landman "End-of-Life decisions, ethics and the law: A case for statutory legal clarity and reform in South Africa" (2012) *Ethics Institute of South Africa* 17-19.

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30 June 2017

Ms Jenny Govender (208513413)  
 School of Law  
 Howard College Campus

Dear Ms Govender,

Protocol reference number: HSS/0965/017M

Project title: Desiring Death: A critical analysis of Advanced Directives within the South African Legal Framework

Approval Notification — No Risk /

Exempt Application In response to your application received on 27 June 2017, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted FULL APPROVAL.

Any alteration/s to the approved research protocol i.e. Questionnaire/interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number,

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr Shamila Naidoo (Deputy Chair)

/ms

Cc Supervisor: Ms Suhayfa Bhamjee  
Cc Academic Leader Research: Dr Shannon Bosch  
Cc School Administrator: Mr Pradeep Ramsewak

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