

# Advance directives or living wills- some reflections from General Practitioners and Frail Care Coordinators in a small town in KwaZulu Natal.

Research assignment submitted in partial fulfilment of  
the MMed in Family Medicine degree

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“Declaration

I, the undersigned, hereby declare that the work contained in this assignment is my original work and that I have not previously submitted it, in its entirety or in part, at any university for a degree. I also declare that ethical approval for the study was obtained from the Health Research Ethics Committee of Stellenbosch University (Reference number: N11/07/236).

Signature: ..... Date:.....

## ABSTRACT

**Background:** - Living wills have long been associated with end-of- life care. This study explored the promotion and use of living wills amongst general practitioners and frail care nursing coordinators directly involved in the care of the elderly in Howick, Kwa-Zulu Natal. The study also explored their views regarding the proforma living will disseminated by the Living Will Society.

**Participants:** - Seven general practitioners and three frail care nursing coordinators, making ten in total.

**Design:** - Qualitative in-depth interviews and analysis, using the Framework method.

**Results:-** Both doctors and nursing staff understood the concept of living wills and acknowledged their varied benefits to patient, family and staff. They were concerned about the lack of legal status. They felt that the proforma document from the Living Will Society was simple and clear. Despite identifying the low level of use of living wills, they felt that third party organisations and individuals should promote living wills

**Conclusion:** - GPs and frail care nurse coordinators were knowledgeable of living wills in general and the Living Will Society proforma document in particular. They valued the contribution that living wills can make in the care of the elderly, benefitting patients, their families, health care workers and even the health system. They also valued the proforma living will document from the Living Will Society for its clarity and simplicity. However, both GPs and frail care nursing coordinators viewed the living will process as patient-driven and their main role was as custodians and not advocates of the living will.

## INTRODUCTION

A living will is a set of instructions that document a person's wishes about medical care intended to sustain their life. It is used if a patient becomes terminally ill, incapacitated, or unable to communicate or make decisions. A living will protects the patient's rights and removes the burden of making decisions from family, friends, and physicians.<sup>1</sup> It also represents a means of clarifying decision making, while empowering patients and enhancing choice.<sup>2</sup>

In South Africa, the Living Will Society more narrowly defines the concept of the living will by noting that its main function is to aid in the “refusal of artificial life-support when dying”.<sup>3</sup> However, a living will may, in addition, contain specific direction regarding the use of antibiotics, analgesia, hydration and feeding.

Living wills are not a new entity and were first suggested by U.S. attorney Luis Kutner in 1967. By 1992, all fifty states, as well as the District of Columbia, had passed legislation to legalize some form of advance directive.<sup>4</sup> In the United Kingdom, the principle of patient involvement in decision making was a key recommendation in the 2004 guideline by the National Institute for Clinical Excellence entitled *'Improving supportive and palliative care for adults with cancer'*.<sup>5</sup> In 2007, the Mental Capacity Act 2005 provided a legal framework in the UK for various elements of advance care planning. This legal foundation became National Health Service policy in the form of a document entitled *'Capacity, care planning and advance care planning in life limiting illness'*.<sup>6</sup> Professional guidance regarding advance care planning was subsequently produced in 2010 by the General Medical Council and was entitled *“Treatment & Care Towards the End of Life”*.<sup>7</sup>

In 1999, a South African bill was proposed entitled the *“End of Life Decisions Act 1999”*. This is contained within the SA Law Commission Report Project 86 *“Euthanasia & the Artificial Preservation of Life”*.<sup>8</sup> This has still not been passed into law in 2011.

Despite the lack of a clear legal framework for the living will in South Africa, the following statement by Prof. D. McQuoid-Mason, a prominent legal academic, suggests that existing legal principle supports it:<sup>9</sup>

*“It is accepted in SA Law that patients have the right to refuse medical treatment, even if it may cause them to die, if they have the legal capacity to make such a decision. In English Law, the Principle extends to situations where the person, in anticipation of his... entering into a Persistent Vegetative State , gives clear instructions that in such an event he is not to be given medical treatment designed to keep him alive. It is submitted that Similar Principles apply in our law where patients have made a Living Will that reflects their current wishes.”*

Advocates of living wills put forward the following arguments for their use:<sup>10</sup>

- They respect patient autonomy and advance the ethical principle of beneficence
- They require informed consent
- They are perceived as important by doctors
- They enhance doctor-patient communication

However, the following criticisms of living wills have also been expressed:<sup>10</sup>

- A lack of individualisation if a template type of living will document is used.
- It may not represent the patient’s true and current wishes.
- It is automatically interpreted as a Do Not Resuscitate (DNR) order.
- It is unavailable in an emergency situation eg Casualty.

The challenge of educating and promoting the living will to the South African population has been taken up by the Living Will Society.<sup>2</sup>

As a primary care clinician in a community with a large number of elderly, it is my impression that the uptake and use of living wills is low. This research aims to explore this impression by assessing the knowledge and attitudes of General Practitioners (GPs) and frail care coordinators, who are responsible for the care of Howick’s elderly residents,

to the use of living wills in general and the proforma living will from the Living Will Society in particular.

## **AIM & OBJECTIVES**

### **Aim**

The study aims to explore the knowledge and attitudes of general practitioners and frail care co-ordinators to the use of living wills in the town of Howick, Kwa-Zulu Natal.

### **Objectives**

- To explore the factors that influence the promotion and use of the living will by Howick general practitioners (GPs) who are involved with the care of the elderly.
- To explore the factors that influence the promotion and use of the living will by frail care nursing coordinators.
- To explore impressions of the SAVES Living Will proforma document by the above stakeholders.

## **METHODS**

### **Study Design**

Qualitative research methodology was used to allow the exploration of attitudes, opinions and experiences.

### **Setting**

The town of Howick, in Kwa-Zulu Natal, is a retirement destination of choice for middle income and above, predominantly white elderly South Africans. Howick And District Care of the Aged (HADCA) are responsible for the provision of 33 assisted living units, 73 frail care beds and 12 dedicated beds for dementia patients. Three other independent retirement complexes, each with frail care facilities and administered by body corporates, comprise a total of approximately 1600 residential units and 168 frail care beds. The frail care coordinators, five in total, are all professional nurses by training whose role it is to coordinate all aspects of holistic care for the residents. Eight doctors from three

independent private general practices provide care for these elderly residents and have had to deal with the issue of living wills.

### **Selection of participants**

All seven GPs (excluding the researcher), who are involved in the care of these elderly residents, were invited and subsequently interviewed; no sampling took place. Out of the five frail care nursing co-ordinators, three were purposefully selected for interview. Selection was based on availability for interview.

### **Data collection**

Interviewees were approached personally by the researcher and invited to participate in the research. The date and time of the interview was decided by mutual agreement and all interviews took place in the participants' place of work or home in the month of September 2011. Participants were interviewed individually and on one occasion only.

Each in-depth interview was conducted in English by the researcher, himself a general practitioner involved in care of the aged in the area, using a standardized, pre-piloted topic guide (see appendix) with facilitative responses and reflective listening statements. The Living Will proforma document was shown to the interviewees for reference. Each in-depth interview was recorded electronically with additional handwritten notes being made where required. The recordings were transcribed verbatim by the researcher.

### **Data analysis**

Data from the in-depth interviews was analysed using the "framework method".<sup>11</sup> This method allowed for a systematic analysis of qualitative data and an explicit research process.

Familiarisation, the first step, involved reading the entire data set of transcripts to provide an overview of their depth and diversity. This overview allowed themes, both anticipated and emergent, to be recognised and annotated. A thematic framework was developed around the topic guide resulting in an index that could be applied to the transcripts. Coded data was then lifted from the transcripts and charted allowing comparison, mapping of themes and interpretation.

During the interview phase concurrent analysis enabled unanswered issues and questions from earlier interviews to be addressed in subsequent ones.

### **Ethical considerations**

Key ethical considerations for this study related to the participants and were informed consent for participation, confidentiality of recorded and transcribed interview material and protection of their interests regarding time and convenience.

Ethics approval for the study was granted by the Health Research Ethics Committee of Stellenbosch University: (Reference No: N11/07/236)

## **RESULTS**

Exploration of participant's understanding of the living will unearthed three major themes: (1) the purpose of the living will; (2) the timing or the stage of life when it is drawn up; and (3) the legality of the living will.

All of the study participants, both GPs and frail care coordinators were aware of the concept of the living will. One of the frail care nursing sisters described a patient's living will as:

*' whilst in a sound mind, giving some guidance or instruction with regard to their medical treatment when they are not necessarily able to speak for themselves, with regard to no heroics ,not resuscitating, no prolonging of life unnecessarily.'*(MJ)

They all acknowledged that the living will is both a statement of wishes regarding end-of-life care as well as a statement of refusal of certain treatment. All of the respondents felt that it is a document applicable to end-of-life or terminal care. However, two GPs made the following observations:

*'..a lot of living wills are completely healthy people with maybe one or two chronic medicines.'*(JP)



*'..the majority are healthy when they come with it, but very often have had a family member who has been kept alive artificially and traumatically.'*(SN)

With regard to the legal status of living wills in South Africa (SA) the GPs all stated that it has none whereas the frail care nursing staff were unsure. The lack of formal legal status of the living will has affected the perceived value of the living will by some GPs. For one GP, its lack of legal status prompted the response:

*'I guess that's why I haven't got too involved with it'. (CJ)*

Those who valued it, felt:

*'It's not legally binding but it certainly is a good directive'. (PD)*

Participants were then asked about the process of drawing up living wills in general, and their role in the process in particular. The themes that emerged related to the sources of the living will document and the roles played by the participants, whether nursing or medical, as well as the patient and their family.

The Living Will Society was the most frequently mentioned source of the living will document and all respondents, both medical and nursing, were aware of it. Other suggested sources were lawyers and even the internet. The internet, although a suggestion, was not thought to be commonly used amongst the elderly in the community. Lastly, a verbal directive with witnesses has been the experience of both a GP and a nurse, the latter fulfilling the role of recording these wishes in the situation of a patient's acute deterioration. This recording of a verbal statement of advance care wishes was the most active role performed by any of the respondents when it came to roles performed in drawing up living wills. Typical responses of the GPs were:

*'If a patient were to ask me should I have a living will, I encourage it. But I must admit that I don't often go and actively promote it.'*(EC)

*'..they come to me with the document already having been signed and just ask me to keep the document in their file.'*(PD)

They saw their role as custodians of the document and not as promoters or initiators of the process.

For the nurses, they facilitated a process that was patient driven.

*'I recommend to the family to get in touch with the Living Will Society and then go through their GP.'*(RC)

Participants were then asked to relate their experiences regarding the use of living wills, identifying benefits or strengths and weaknesses.

The benefits of living wills as identified by the respondents can be divided into those experienced by doctors, nursing staff, families and the patients themselves. Living wills can also benefit the use of resources in the health system.

Those doctors, who found the living will a useful tool, spoke of its value in decision making:

*'In my final decision for an end of life issue...it makes it easier and it weights a decision in favour of what a living will says.'*(EC)

They used the living will to show congruency between their proposed management plan and the patient's stated wishes. In this way their management plan was reinforced. Living wills were used:

*'..to let the family know that the decision-making is not so much from your side, but rather from the patient's side.'*(SN)

The nurses also highlighted the benefit a living will offers when implementing a palliative care plan for a patient in a frail care facility.

*'I like the living will in the fact that it gives us guidance...it just enables us to do that without feeling guilty, we just know that it is what everybody wants.'* (MJ)

Both doctors, including those not partial to the use of living wills, and frail care nurses saw living wills offering real value to families in terms of decision-making, including conflict resolution, and grieving.

*'..if they know what their mother or father's wish was, it's easier for them to accept that. They feel unfaithful if they give up every attempt of promoting life.'* (SM)

Lastly, and perhaps most importantly, one of the benefits identified was to patients.

*'Having a formalized document like the living will helps people think about the unthinkable.'* (CJ)

*'..it also makes people come to terms with their mortality.'* (SM)

One of the frail care coordinators felt that living wills helped with the appropriate use of health care resources.

*'I think if we had to send down to hospital everyone who had a stroke...there would be a lot of overflow in the hospitals and the staff cannot cope with it.'* (RC)

When addressing weaknesses in the living will process, both nurses and doctors agreed that living wills were not widely used. A recently opened frail care facility illustrated this point. The nursing manager commented:

*'I've got 42 permanent residents...and only 2 of the permanent residents have living wills.'* (MJ)

The participants felt that this reflected a lack of exposure to and knowledge of living wills:

*'My impression is that the elderly are not well informed in SA about living wills.'*(EC)

*'I was just thinking of who my patients (are) who have got living wills. A lot of them are medical or paramedical and maybe it's the background that they know...so that's why patients haven't gone into it, is it because they haven't been exposed to it?'*(VP)

For those who had completed a living will, its use could still be compromised by problems with availability. Both the GPs and frail care sisters recognised their responsibility for keeping living wills and making them available when needed. However, one GP observed:

*'..sometimes it is not known that a living will is in place because they've changed institution of care and the new institution is not fully versed in what the patient's wishes were.'*(SM)

Even when availability of the living will was secured, commented one GP, it was appropriate and important to assess whether it still represented a current expression of the patient's wishes:

*'..if the time...it was long ago, it may be old and the context and situations may have changed. This may make the living will difficult to interpret.'*(EC)

Having looked at some strengths and weaknesses of the living will, the participants were then asked to consider ways in which the use of the living will could be improved. The majority identified the need for improved knowledge and awareness amongst the population.

*'I think it is basically increased awareness. The bottom line- people are either going to be interested or not.'*(MJ)

The respondents identified a variety of ways to promote and educate regarding the living will. It was suggested that promotional and educational materials could be made available in practice and hospital waiting rooms, frail care facilities, Hospice, organisations involved with care of the aged (e.g. HADCA), pharmacies, and even the communal activity areas of the various residential complexes. Educational articles in local newspapers were likely to be widely read. Community forums and focus groups could host educational talks. Specific input from the legal profession would educate both medical staff and community members alike.

All the participants who considered the living will a useful tool identified the proforma living will from the Living Will Society as the most commonly used. They commented favourably on its simplicity, standardisation and clarity.

*'I don't think you can itemise every situation you might find yourself with. I think it's broad enough to cover a lot of situations. If it is to itemise every situation, then it's going to be quite clumsy.'*(MJ)

*'It's a fairly standardised document. Otherwise, everyone puts in their own feelings and beliefs in what's going on.'*(SN)

Interestingly, one GP, who had had experience of a patient with a terminal diagnosis and predictable acute complications, felt that under these conditions living wills:

*'can be improved if they are more specific.'*(VP)

## DISCUSSION

### Key findings

In this study, both GPs and frail care nurses were familiar with the concept of the living will and highlighted its role in preserving patient autonomy, allowing more patient-centred care, guiding clinical decision making and the rational use of resources, and facilitating family involvement in appropriate end-of-life care. Despite concern over a lack of legal status, the majority still valued the guidance that living wills provided. Even so, all participants agreed that very few were completed in practise, an observation that is also noted in other research.<sup>12</sup> A lack of awareness of living wills was put forward as an explanation of the poor uptake. Both nurses and doctors acknowledged that they acted as the custodians of living wills rather than promoters or advocates. Their proposal for the improvement of patient awareness revolved around educational and promotional talks and articles. The concerns of doctors and nurses regarding initiating the living will process related to the sensitivity of the subject and the time required. However, research suggests that the best uptake of advance care planning results from a physician initiated process.<sup>13,14,15</sup>

The Living Will Society has promoted the living will through a patient driven process focussed around a proforma living will document that appears suitable for our local needs. Although the legal status of the living will remains untested in South Africa, Emanuel eloquently comments that the value of the living will is in the process of advance care planning and not its legal status:<sup>16</sup>

*'Moving away from the notion of a legal defence against aggressive doctors, the living will movement realised that it is the process that is the central issue. Eventually, living wills came to be seen as a vehicle for achieving greater wisdom and skill in a fundamental aspect of health care and a civilised approach to mortality. Advance care planning is a process of discussion, a component of care. Legal documentation has a small but legitimate role.'*

There is a growing trend of international opinion regarding an advance care planning process rather than the completion of a legal document only.<sup>17,18,19</sup> Research also points to the value of physician initiated advance care planning as a means to increase uptake. This suggests that it may be time for doctors and nurses to meet their patients halfway by embracing their role of initiating advance care planning.

### **Strengths and limitations of the study design**

A strength of the study relates to the interviewing of all of the GPs involved in the care of the elderly through the various frail cares in Howick. A weakness of the study is its lack of generalisability beyond a white, middle class elderly South African population in a specific primary care setting. It is also possible that nurse participants may have felt intimidated by a doctor conducting the interviews. Interview techniques involving facilitative responses and reflective listening statements helped to overcome this. With interviews and analysis being conducted by one person whose personal perspective was favourable towards the use of living wills there was the possibility of bias being introduced. However, with only two participants not finding value in living wills and both of those general practitioners who were confident of their opinion, this seems unlikely.

### **Implications and recommendations**

The insight into the knowledge of, attitude to and use of living wills is going to be valued by HADCA, Hospice, the frail care committees of the various residential communities and the Living Will Society. The participants involved will benefit from the insights of their colleagues. Primary health care providers serving communities with a similar population demographic will also find the results interesting and the discussion relevant. This research suggests that a plan of action to promote knowledge and use of living wills within the community is required.

Further research is needed to evaluate whether these findings are generalisable to primary care clinicians working in other cultures and socioeconomic communities. It would also

be appropriate to explore how advance care planning is conceptualised by stakeholder organisations and clinicians involved in aged care and end-of-life care.

## **CONCLUSION**

All the participants, both medical and nursing, were knowledgeable of the living will in general and the Living Will Society proforma document in particular.

The research showed that the majority of GPs and frail care nurse coordinators valued the contribution that living wills can make in the care of the elderly, benefitting patients, their families, health care workers and even the health system. They also valued the proforma living will document from the Living Will Society for its clarity and simplicity. However, both GPs and frail care nursing coordinators viewed the living will process as patient-driven and their main roles as custodians and not advocates of the living will. To meet the challenge locally of poor uptake of living will use, it is suggested that GPs and frail care coordinators consider the process of advance care planning and defining their roles within it.

## **ACKNOWLEDGEMENTS**

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## APPENDIX 1: PARTICIPANT INFORMATION LEAFLET

**TITLE:**

Advance directives or living wills- some reflections from General Practitioners (GP's) and Frail Care Coordinators in the town of Howick, KwaZulu Natal.

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Dr A.P.A.Bull

**ADDRESS:** Department of Family Medicine, University of Stellenbosch.

**CONTACT NUMBER:** 082 5579079

Dear Colleague,

My name is Dr Alastair Bull and I am a General Practitioner. I would like to invite you to participate in a research project that aims to explore how general practitioners or frail care coordinators involved in the care of the elderly, feel about living wills and their use here in Howick.

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

To investigate your ideas and feelings regarding living wills I would like to interview you. The interview will take approximately 1 hour and is recorded for future transcription and analysis. Participation carries no risk. The information from the interviews will help us to understand better how healthcare workers, providing care to the elderly in Howick, regard living wills and their value, as well as issues regarding their use.

The information collected during the interviews will be treated as confidential. It will be included in a thesis and may be published without the identity of the participants being disclosed. All participants will have access to the findings should they so wish.

**If you are willing to participate in this study please sign the attached Declaration of Consent and return it to me.**

Yours sincerely

Dr Alastair Bull, Principal Investigator

## Declaration by participant

By signing below, I ..... agree to take part in a research study entitled '**Advance directives or living wills- some reflections from General Practitioners (GP's) and Frail Care Coordinators in the town of Howick, KwaZulu Natal**'.

.

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....

On (*date*) ..... 2011.

.....

Signature of participant

## Appendix 2: **Topic guide:**

1. What do you understand by the term 'living will'?
2. How are living wills drawn up?
3. Do you play any role in the drawing up of living wills? If not, why not?
4. What is your experience regarding the implementation of living wills?  
(highlight strengths and weaknesses)
5. If you feel they are a valuable tool for patient care, how can their use be improved here in Howick?
6. Do you feel that the living will produced by the Living will society is adequate for your patients' care?

Appendix3:

# THE LIVING WILL

## TO MY FAMILY, MY PHYSICIAN AND ANY HEALTH AUTHORITY:

This **advance directive** is made by me

Full Name: .....

Address: .....

.....

.....

at a time when I am of sound mind and after careful consideration.

If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.

If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I do not give my consent to having my dying process prolonged by artificial means, including any pacemaker, nor do I give my consent to any form of tube-feeding when I am dying; and I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress even if the moment of death is hastened.

**DO NOT RESUSCITATE: I do not give my consent to any person's attempt at resuscitation, should my heart and breathing stop and my prognosis is hopeless.**

This declaration is signed and dated by me in the presence of the two undermentioned witnesses present at the same time who at my request in my presence and in the presence of each other have hereunto subscribed their names as witnesses.

Signature: .....

Date: .....

**N B:** Witnesses should NOT be family members or your personal medical practitioner/s, nor should they be beneficiaries in your Last Will and Testament.

**WITNESSES:** .....

Signature .....

Signature: .....

Name: .....

Name: .....

Address: .....

Address: .....

.....

.....

**NOTE:** Should they wish, any person has my concurrence to apply for a court order to ensure compliance with this directive should any medical practitioner or health authority refuse to give effect to it.

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**SAVES – The Living Will Society**

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