dying with DIGNITYSA
my life my choice

Advance Directive / Living Will
PLANNING GUIDE

Table of Contents

Page 2	Understanding your Advance Directive
Page 4	Considering your personal values
Page 6	Considering your medical priorities
Page 8	Why you should name a medical proxy
Page 9	Is your medical proxy up to the job?
Page 10	Talking to your medical proxy
Page 12	Completing the Advance Directive
Page 14	Appendix I. Medical terms explained
Page 15	Appendix II. Frequently asked questions
Page 16	Appendix III. Fact sheet for Medical Professionals in SA
Page 19	About DignitySA
Page 20	Wallet Advance Directive notification card
Page 21	Codicil ~ Remember us in your Will

Endorsed by:

HPCA care & support
Hospice Palliative Care Association of South Africa

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Understanding your Advance Directive/Living Will

What it means

Advance Directives, also known as Living Wills, are documents in which you make known your wishes for your personal care, and for your medical treatment or non-treatment. It only comes into effect if you are found to lack capacity to make personal decisions.

"An 'advance directive' is an arrangement made by competent persons regarding their healthcare treatment in the eventuality that they might become incompetent to make their own healthcare decisions. Such directives may be about the circumstances surrounding possible future treatment, the kinds of treatment, or by whom decisions should be made. There are two main classes of advance directives:

- A 'living will' is an instruction directive by means of which a competent person instructs others to withhold or withdraw potentially life-sustaining treatment should they become incompetent to refuse such treatment themselves. For example, a person may sign a document instructing others to withhold or withdraw all medication such as antibiotics and including artificial nutrition and hydration, should they fall into a permanent vegetative state (PVS) or become irreversibly non-responsive.
- A 'durable power of attorney for healthcare' is a substitute directive by means of which a competent person appoints or mandates a specific person as their substitute (proxy, surrogate) healthcare decision-maker should they become incompetent to make their own healthcare decisions. Such a power of attorney may confer general decision-making powers on the substitute, for example, to make all healthcare decisions – including decisions about refusal (withholding and withdrawal) of potentially life-sustaining treatment – on behalf of the patient. In addition, the substitute decision-maker may also be given specific instructions, for example to refuse potentially life-sustaining treatment in foreseen circumstances, such as severe and irreversible lack of brain function. This kind of power of attorney is durable because once the patient becomes incompetent it remains in effect.

Why you should have an Advance Directive

In a medical emergency, or any other circumstance which leaves you unable to communicate, your Advance Directive/Living Will will help those responsible for your care to decide on your treatment. And it will help your loved ones to make the right decisions on your behalf.

Without an Advance Directive you may be subject to aggressive medical intervention, which you may not want to have. Or you may have a specific medical condition for which you do want all available treatment.

Speak with your doctor or medical practitioner

It is important that you discuss your health care desires with your doctor or medical practitioner. He or she is likely to be the one caring for you when your instructions become relevant and is much more likely to honour requests that have been communicated directly. Your doctor or medical practitioner can:

- Help you phrase your requests in a way that makes sense to medical professionals and can answer any questions you may have.
- Point out any illogical or inconsistent features of your requests. Sometimes refusing one kind of treatment makes it illogical to expect to receive another kind of treatment. Your doctor or medical healthcare giver can smooth out some of these "rough edges" and help make a consistent and coherent directive.
- Tell you if there are aspects of your requests that he or she cannot honour because of personal, moral, or professional or legal constraints.

Discuss with your family

Despite your best efforts to plan for all eventualities in a health care declaration, actual events may not "fit" your directives. It is therefore important that you discuss your desires with family and friends.

- Your family can often help clarify your directives on the basis of recollections of specific discussions under specific circumstances.
- If you have discussed your wishes with a number of people, it is more likely that those wishes will be honoured.
- Discussions with family members can help avoid unpleasant scenes and confrontations when you are incapacitated. While family members may have little legal authority to make decisions for incapacitated patients, they often feel they have moral authority. They may be confused by statements not previously shared with them, and may even try to contest your wishes legally if they feel your choices are not in your "best interest."

Planning ahead with an Advance Directive can give your principal caregiver, family members, and other loved ones' peace of mind when it comes to making decisions about your future health care. It lets everyone know what is important to you, and what is not.

Talking about death with those close to us is not about being ghoulish or giving up on life, but a way to ensure greater quality of life, even when faced with a life-limiting illness or tragic accident. When your loved ones are clear about your preferences for treatment, they're free to devote their energy to care and compassion.

Activating your Advance Directive:

Providing many trusted individuals with copies of your advance directive will ensure that your health care wishes are met in the event that you cannot express your wishes for yourself. Keep the original copy of the Advance Directive in a place that can easily be found, and give copies to:

- Your chosen Medical Proxy (with directions on where to find the original).
- Family members or other loved ones.
- Your primary doctor, hospital, or health care institution. Ask that a copy is placed in your medical record and make sure your doctor will support your wishes.
- Anyone named in the directive.

A copy can also be sent to your attorney or kept in a safety deposit box or anywhere else you may keep copies of a will or other important papers. Be sure that you have discussed the directive with the person you designate as your Medical Proxy and that he or she understands your wishes and the responsibilities involved.

How to go about making an Advance Directive

First, read 'Considering Your Personal Values' in the next section. This will start you off thinking about what is important to you in terms of quality of life.

Considering your Personal Values

1. What do you feel gives your life its purpose and meaning?

2. What do you particularly value about your physical or mental well-being:
    - ❖ Do you most love to be outdoors?
    - ❖ Are large family gatherings your happiest times?
    - ❖ Do you prefer quiet time alone listening to music or reading?
    - ❖ Have you a favorite pastime such as bridge or crosswords?
    - ❖ Do you have a hobby, perhaps painting or collecting?

3. If you were no longer able to enjoy the things that are important to you because of deterioration in your sight, or hearing, or mobility, do you think this would affect the health care decisions you would make?

4. If you could plan it today, what would the last day of your life be like?
    - ❖ Where would you be?
    - ❖ What would you be doing?
    - ❖ Who would be with you?
    - ❖ What would you eat, if you were able to eat?
    - ❖ Would you want the comfort of spiritual support, such as a member of the clergy or someone who shares your religious beliefs?

5. Are there people to whom you would want to write a letter, or tape a message, perhaps marked for opening at a future time?

6. How do you want to be remembered? If you were to write your own obituary or epitaph, what would it say?

7. Are there other personal values you want others to be aware of?

Next

Read 'Considering Your Medical Priorities'. This is the most difficult part, because it asks you to imagine yourself in various critical conditions, and to then think about what treatment you would want to accept or refuse in each case, and to write down your answers.

Writing down your answers is just for your own information and to help clear things in your mind, so that you are better prepared for the next step.

Although death is an inevitable part of life, many of us are reluctant to face the fact that we're not going to live forever and plan for our end-of-life care. Thinking about your end-of-life choices today can improve your quality of life in the future and ease the burden on your family. Discussing your wishes with loved ones and preparing an Advance Health Care Directive offers the best assurance that decisions regarding your future medical care will reflect your own values and desires.

While most people would prefer to die in their own homes, the norm is still for terminally-ill patients to die in the hospital, often receiving ineffective treatments that they may not really want. Their friends and family members can become embroiled in bitter arguments about the best way to care for the patient and consequently miss sharing the final stage of life with their loved one. Also, the opinions and wishes of the dying person are often lost in all the chaos."

Considering your Medical Priorities

1. Which of the following do you fear **most** near the end of life?

Being in pain	
Losing the ability to think	
Being a burden on loved ones	
Other: _____	

2. Is it more important for you to (a) have your wishes for treatment followed at the end of life even if family members or friends disagree, or (b) have family and friends all in agreement and comfortable with whatever decision is made?

Have your wishes for treatment followed, even if there is disagreement	
Have family and friends all in agreement	
I am uncertain	

3. Imagine that you are now seriously ill, and doctors are recommending chemotherapy which sometimes may have severe side effects, such as pain, nausea, vomiting and weakness that could last 2-3 months.

   Would you be willing to endure the side effects if the chance of regaining your current health was less than 25 in 100?

Yes		No		I am uncertain	

4. In the same circumstances as in the previous question, suppose that your condition is clearly terminal, but the chemotherapy has an 80% chance of giving you an additional six months of life.

   Would you want the chemotherapy even though it could have severe side effects, such as pain, nausea, vomiting and/or weakness? Bear in mind that pain control can be achieved for the majority of patients without significant side effects.

Yes		No		I am uncertain	

5. Imagine that you had a dementia, such as Alzheimer's disease, and it had progressed to the point where you could not recognise or have a conversation with your loved ones.

   When spoon-feeding was no longer possible, would you want to be fed by a tube into your stomach?

Yes		No		I am uncertain	

6. Imagine you had advanced dementia to the same degree as in the above question. You have already been hospitalized twice in the past year for pneumonia and other lung infections which required aggressive medical intervention requiring antibiotic medication.

The next time you get pneumonia, which if left untreated could be fatal, do you want aggressive treatment again, or would you prefer simply to have comfort care until death comes?

Aggressive treatment including antibiotics	
No treatment, comfort care only	
I am uncertain	

7. Imagine you have long-standing diabetes, or a severe circulatory condition such as advanced arterial disease that resulted in one leg being amputated because it developed gangrene. Now, the other leg develops gangrene and the doctor recommends amputation because the condition could be fatal. Would you want the operation or would you prefer to simply have comfort care and allow your untreated medical condition to bring about your death?

I would want the surgery	
No surgery, comfort care only	
I am uncertain	

8. Imagine you have congestive heart failure that causes your lungs to fill up with fluid, leaving you extremely breathless, and that also causes your ankles to swell up so that walking is difficult. You are always short of breath and tired, and unable to walk even one block. Your health is poor but you are alert and able to enjoy time with family and friends. One day you have a heart attack and your heart stops beating. Would you want CPR started and emergency services called?

Yes		No		I am uncertain	

9. Imagine that you are in a permanent coma and your body is maintained by artificial means, such as mechanical breathing and tube feeding. Would it be important to you that decisions about your treatment or discontinuation of treatment be guided by the religious beliefs or spiritual values that you hold?

Yes		No		I am uncertain	

10. If you were terminally ill with a condition that caused you much pain, would you want to be sedated even to the point of unconsciousness, if it were necessary to control your pain? (This will most likely be a very rare event.)

Yes		No		I am uncertain	

11. Would you allow yourself to be placed on life support if your heart, kidneys, pancreas, lungs, or liver could be used in transplant operations to save lives after your death?

Yes		No		I am uncertain	

When you are ready to continue, **THE NEXT STEP** is to think about naming a Medical Proxy. Your Medical Proxy is the person you authorise to make decisions on your behalf if you are unable to speak for yourself.

Although naming a Medical Proxy in your Advance Directive is optional, we strongly advise that you do so.

It is important that your Proxy is familiar with your religious values as it relates to what treatment your religion dictates you may or may not receive (e.g. blood transfusion).

Why you should Name a Medical Proxy

If you become critically ill, and unable to communicate your wishes, the doctor or medical healthcare givers treating you will consult with your Medical Proxy concerning the terms of your directive. This gives you another layer of protection in ensuring your wishes are respected.

Although you may have written an Advance Directive, a situation may arise where your medical condition at the time is not one that is addressed in your directive. Your Medical Proxy would then be able to make a decision on your behalf, based on his/her understanding of what you would decide for yourself, if you were able to do so.

Should you suffer a mental impairment, are unable to communicate your wishes, and your lack of capacity has been confirmed, your Medical Proxy has the authority to make arrangements for your personal care. Your Medical Proxy is concerned with all aspects of your future care, such as where to live; whether or not you have special dietary or clothing needs, and if so, to ensure these needs are accommodated; arranging for additional help to assist you in daily living, should you gradually come to need this.

Who to Appoint

Your Medical Proxy must be over 18 years of age, someone who knows you well and whom you trust to carry out your wishes. You should **not** appoint anyone who provides you with health care or support services for compensation, unless you are sure there is no conflict of interest. Any Medical Proxy involved in your care must be authorised by name and not by the title of the position they occupy.

You have the option to appoint more than one Medical Proxy. In this instance you should name one person as Primary Medical Proxy, and the next person as Alternate Medical Proxy. If you name more than one person, you may choose to have them act **jointly** or act **independently**.

Having them act jointly means they must all agree on all decisions before action can be taken. This can lead to disagreements or misunderstandings, and can be very time-consuming.

Having them act independently means that if the person you named as Primary Medical Proxy is unavailable or unable to act on your behalf, the person you named as Alternate Medical Proxy is automatically authorised to assume the duties.

We advise that you name your Medical Proxies to act independently.

Is your Medical Proxy up for the job?

Crucial questions to have your Medical Proxy consider before agreeing to become your Medical Proxy.

Every Advance Directive needs both a '*what*' (a document outlining the patient's treatment preferences) and a "*who"* (an individual who will speak for a patient who can't speak for themselves).

"Pulling the Plug" is a term used to include everything from turning off a ventilator to withdrawing medically assisted nutrition and hydration and, for clarity, the Medical Proxy will not, themselves, physically withdraw treatment or 'pull the plug'. This task is assigned to the medical practitioner.

1. **Will I 'pull the plug'?** A Medical Proxy may be called upon to refuse consent to or authorise discontinuation of life-sustaining medical care. If religious or moral views could prevent you from ensuring the patient's wishes are carried out, you should decline the role

2. **Can I 'pull the plug'?** Sometimes the most likely candidates to serve as a Medical Proxy aren't the best ones because they are too close to the patient. Emotions can cloud their thinking. Spouses in particular have been known to falter when it comes to a decision on ending futile treatment, even when they know it is what the patient wants. They simply can't bring themselves to 'pull the plug'.

3. **Can I 'pull the right plug**'? Am I able to understand the medical decisions involved and willing to spend the time to really understand the diagnosis, treatment alternatives and potential side effects? It's important to be willing to act, but it's just as essential to make competent, informed decisions. Medical terminology and possible treatments are contained at the end of this document.

4. **Am I willing to be an advocate?** In the best of all possible worlds, you'll reach your decisions and find that the patient is treated accordingly. But sometimes you'll need to challenge the system and advocate for the patient. Why is the terminal patient still being given blood tests when her body language indicates they hurt? Why is a patient suffering advanced dementia being given antibiotics when you know he didn't want any life-prolonging measures? As the Medical Proxy on the scene, you have a critical role to play.

5. **Am I young enough for the job?** It's one thing to say yes, quite another to have the health and energy to do it when the time comes. And that time may not come for several years.

6. **Have I completed the Medical Proxy questionnaire in the patient's Advance Directive**? This is an essential step to confirm that you really understand the patient's wishes. Sometimes a prospective Medical Proxy may reconsider taking on this role when they've looked at the medical scenarios described in this questionnaire and realise the kind of decision they may have to make for someone else.

7. **Am I willing to say *"it's not about what I would want. It's what you want?"*** This is the most critical test. Everyone is different, and we all have different ideas about end of life care. We may want to literally keep fighting for our lives and decide to accept all appropriate medical care or we may want a gentle death and decide to stop unwanted treatment. As a Medical Proxy, you must set aside your personal values and act in accordance with the patient's wishes.

Talking to your Medical Proxy

Your Medical Proxy is the person you will authorise to speak on your behalf. How well do they know you and your health care wishes? This short form with questions and answers will help you find out how well you have communicated your wishes to them and how well they have understood your wishes.

This is exactly the same form as Considering Your Medical Priorities, which you filled in earlier. Your Medical Proxy now answers the same questions as if they were doing so on your behalf, under conditions in which you could not speak for yourself.

****** Your Medical Proxy completes this section ******

1. Which of the following do you think I fear **most** near the end of life?

Being in pain	
Losing the ability to think	
Being a burden on loved ones	
Other: _____	

2. Do you think it is more important for me to (a) have my wishes for treatment followed at the end of life even if family members or friends disagree, or (b) have family and friends all in agreement and comfortable with whatever decision is made?

Have my wishes for treatment followed, even if there is disagreement	
Have family and friends all in agreement	
I am uncertain	

3. Imagine that I am now seriously ill, and doctors are recommending chemotherapy and that this treatment can sometimes have severe side effects. Do you think that I would be willing to risk/endure the potential side effects if the chance of regaining my current health was less than 25 in 100?

Yes		No		I am uncertain	

4. In the same circumstances as in the previous question, suppose that my condition is clearly terminal, but the chemotherapy has an 80% chance of giving me an additional 6 months of life.

   Do you think that I would want the chemotherapy even though it has severe side effects, such as pain, nausea, vomiting and weakness?

Yes		No		I am uncertain	

5. Imagine that I had a dementia, such as Alzheimer's disease, and it had progressed to the point where I could not recognise or have a conversation with my loved ones.

   When spoon-feeding was no longer possible, do you think that I would want to be fed by a tube into my stomach?

Yes		No		I am uncertain	

6. Imagine I have advanced dementia to the same degree as in the above question. I have already been hospitalised twice in the past year for pneumonia and other lung infections, which required aggressive medical intervention, including massive doses of antibiotics.

   The next time I get pneumonia, which if left untreated could be fatal, do you think that I would want aggressive treatment again, or that I would prefer simply to have comfort care until death comes?

Aggressive treatment including antibiotics	
No treatment, comfort care only	
I am uncertain	

7. Imagine I have long-standing diabetes, or a severe circulatory condition such as advanced arterial disease that resulted in one leg being amputated because it developed gangrene. Now, the other leg develops gangrene and the doctor recommends amputation because the condition could be fatal.

   Do you think that I would want the operation or that I would prefer to simply have comfort care and allow the untreated medical condition to bring about my death?

I would want the surgery	
No surgery, comfort care only	
I am uncertain	

8. Imagine that I am physically frail and need help with most routine daily activities, such as dressing, bathing, eating, and going to the toilet. I live in a nursing home and my mind is fairly clear and capable most of the time. I develop a severe kidney infection which has failed to respond to simple antibiotics and which, if left untreated could prove fatal through multiple organ failure.

   Do you think that I would want to be hospitalised and receive aggressive medical intervention, or that I would prefer not to be treated, but simply to have comfort care and allow the untreated medical condition to bring about my death?

Treated in hospital	
No treatment, comfort care only	
I am uncertain	

9. Imagine I have congestive heart failure that causes my lungs to fill up with fluid, leaving me extremely breathless, and that also causes my ankles to swell up so that walking is difficult. I am always short of breath and tired, and unable to walk even one block. My health is poor but I am alert and able to enjoy time with my family and friends.

   One day I have a heart attack and my heart stops beating. Do you think that I would want CPR started and emergency services called?

Yes		No		I am uncertain	

10. Imagine that I am in a permanent coma and my body is maintained by artificial means, such as mechanical breathing and tube feeding.

    Do you think it would be important to me that decisions about my treatment or discontinuation of treatment be guided by the religious beliefs or spiritual values that you know I hold?

Yes		No		I am uncertain	

11. If I were terminally ill with a condition that caused me much pain, do you think that I would want to have my pain controlled with pain killers that may cause me to be sedated to the point of unconsciousness?

Yes		No		I am uncertain	

12. Do you think that I would allow myself to be placed on life support if my heart, kidneys, pancreas, lungs, or liver could be used in transplant operations to save lives after my death?

Yes		No		I am uncertain	

Compare the answers your Medical Proxy has given with the answers you wrote down for yourself. This will tell you if your Medical Proxy understands you well and understands the wishes you have expressed for your future personal care and medical treatment, and is willing to act on your behalf.

The Final Step

Read the Advance Directive Form all the way through but do not start to fill in the form until you have read the directions on how to do so.

Make sure you completely understand all the information and are satisfied that your Medical Proxy understands that these are your wishes, and is willing to act on your behalf. You will then be ready to complete your Advance Directive Form and appoint your Medical Proxy.

Completing the Advance Directive

Read each line carefully and strike out any that does not apply to you, or that you do not agree with. There are extra spaces for you to fill in any circumstances not covered – e.g. you may have a hereditary condition you want to address.

Add your initials to each line where marked, to confirm that this is your decision.

Signing and making copies

You will need 2 (two) witnesses to your signature. The witness must sign the Advance Directive Form and also write his/her initials beside yours. The witnesses in effect confirm that you have signed the document in their presence and in the presence of each other.

Make copies of the form before you sign and date, so that each copy has the original signatures.

The following persons may not act as witness

- *A person named in the directive as a Proxy;*
- *The spouse or partner of a person named in the directive as an Proxy;*
- *Your own spouse;*
- *A person who signs your directive on your behalf if you are unable to do so and to whom you are giving your instructions verbally.*

Talk to your doctor

Talk to your doctor or medical healthcare giver and ask that a copy of the directive be entered in your medical records. Give a copy to whoever will be making decisions on your behalf if you cannot do so for yourself. Keep a copy where it can be easily found in an emergency situation. Leave a note in a prominent place – perhaps with a fridge magnet – saying where to find your Advance Directive and who to call in an emergency**.**

Changing your mind

You can always change your mind. This is important, since we all have to adjust to changes in life circumstances, including health status. Therefore we advise that you review your Advance Directive at least every three years. If there are no changes to be made, sign it again with the new date. There is space at the bottom of the form for you to do this.

There is no requirement under law that you update your signature. However, we advise you to do so. Your Advance Directive may not come into effect for some considerable time. If you have not updated your signature, there is no evidence that you have recently reviewed your Advance Directive and that your wishes are unchanged.

Your new signature and date has to be witnessed regardless if you are making changes to the terms of your directive or not.

If your medical condition has changed, or if you have reconsidered some of the answers you wrote down, ask us to send you a new form, and start over. Begin by revoking your previous Advance Directive and continue on as before.

Also, remember that we all adjust to changes in life circumstances, including health status, so you may well change your mind. You may find that your actual symptoms are not as ghastly as you'd imagined they would be when completing this document. Be sure to tell everyone involved in your care that you have revised your Advance Directive.

Some good advice from the American Bar Association

Re-examine your health care wishes every few years or whenever any of the "Five D's" occur:

1. Decade – when you start each new decade of your life.
2. Death – whenever you experience the death of a loved one.
3. Divorce – when you experience a divorce or other major family change.
4. Diagnosis – when you are diagnosed with a serious health condition.
5. Decline – when you experience a significant decline or deterioration of an existing health condition, especially when it diminishes your ability to live independently.

Our recommendation would be to re-examine it annually –
e.g. on your birthday, or, perhaps, New Year's Day.

Appendix I

Medical Terms Explained

Antibiotics: drugs commonly used to successfully treat infections. Some of these infections can be life-threatening for a grievously ill person. Examples would be pneumonia or an infection in the blood or brain.

Artificial Nutrition: being fed by a method other than by mouth. This would apply if you were in a coma or otherwise unable to swallow, and may be by:

Nasogastric Tube (NG tube) - a tube inserted through the nose and into the stomach. The tube may also be used to suction excess acids from the stomach.

Gastrostomy tube (G-tube or PEG tube) – a tube placed directly into the stomach for the long term administration of food, fluids and medications.

Artificial Hydration: being given fluids via a small tube inserted into a vein (venous catheter or IV). Terminal patients who wish to voluntarily stop eating and drinking (VSED) and to simply receive comfort care, should also request to discontinue artificial hydration by IV, as this prolongs the dying process.

Cardio-Pulmonary Resuscitation (CPR): applying pressure to the chest, or an electric charge to re-start the heart, and sending air directly into the lungs to assist in breathing. CPR can be life-saving, but the success rate for critically ill patients is extremely low.

***Cerebrovascular Accident (CVA*)**: see *Stroke*

Chronic debilitating suffering of a permanent nature: a medical condition for which there is no cure. Examples would be Parkinson's disease or terminal cancer.

Coma: a profound state of unconsciousness in which a person cannot be awakened by pain, light, sound or vigorous stimulation. There may be some movements but these are not conscious acts. A patient in a coma state which is of short duration can recover. Over four weeks in coma, the patient may progress to a vegetative state.

Comfort Care: for the dying patient when further medical intervention is rejected or has been judged futile.

Dementia**:** a condition that affects the ability to think and reason clearly and impacts on a person's ability to perform everyday functions. An example would be Alzheimer's disease.

Heart Failure: a condition where the heart is damaged and fails to pump enough blood to the critical organs in your body.

Hospice Care: for terminal patients, and may be given in the home or in a hospital or care facility. The emphasis is on pain and symptom control for the dying patient, and there is normally no aggressive medical treatment.

Intensive Care Unit (ICU): sometimes referred to as the Critical Care Unit is a hospital ward with highly specialised staff. It is for the patient with a life-threatening illness or injury, including major surgery with a threat of complications, which needs constant monitoring and the support of specialised equipment.

Life-sustaining treatment: replaces or supports defective bodily functions. It may be used temporarily for a treatable condition until the patient is stabilised. If there is no hope of the body regaining the ability to function normally, life support may simply prolong the dying process without the benefit of increased quality of life.

Mechanical Breathing: used to support or replace the function of the lungs. The ventilator or respirator is a machine attached to a tube inserted into the patient's nose or mouth and down into the windpipe, in order to force air into the lungs. It helps people with a short term medical problem. People with irreversible respiratory failure such as that caused by injury to the spinal cord, or a progressive neurological disease will require long term ventilation; and in this case, the tube is inserted through a small hole at the front of the throat into the trachea (tracheotomy tube).

Palliative Care: can be delivered to patients in their own homes by palliative care trained nurses and home-based carers. Sometimes hospital admission will be necessary. Palliative care may be given in conjunction with medical treatment such as chemotherapy or radiation. The emphasis is on pain and symptom control, and the management of side effects of the treatment, such as weakness and nausea.

Stroke: damage to the brain caused by a blockage of blood flow, or bleeding into the brain. The degree of disability resulting depends on the location and severity of the initial cause.

Terminal illness: a medical condition which has progressed to the point where death may be expected within weeks or months.

Vegetative State: a result of damage to the parts of the brain that control thinking, memory, consciousness and speech. The patient may have no damage to the part of the brain that controls breathing and heart rate, and may continue to survive in an unresponsive state.

Appendix II

Frequently Asked Questions

Q - Can someone else create an Advance Directive on my behalf?

A - *No. But if you are unable to write, your directive may be given orally and written down by someone else, whose signature must be witnessed in your presence.*

Q - What if I have a written Advance Directive in which I refused a certain treatment, and then when in hospital I change my mind?

A - *You can change your mind at any time. Any instructions you give orally will over-ride previously written instructions provided you are competent when you express them.*

Q – I am just not comfortable imagining all these medical conditions you describe. Why can't I simply say I don't want my dying to be prolonged?

A – *You may certainly do so. Many people have a general directive such as this. However, if you do not set down specific instructions, your Advance Directive is open to interpretation and you may be treated in ways you would not want.*

Q – My son is named as sole Medical Proxy in my directive. If he moves out of the country can he delegate one of my three daughters to act instead?

A **–** *No. You would have to make out a new Advance Directive naming one of your daughters as Primary Proxy. To prevent a similar situation arising, you should also name each of the other daughters in turn, as second and third Alternate Medical Proxies, and we advise that you appoint them to act individually rather than jointly.*

Q – I have two sons and I want to give them equal rights. Why should I not appoint them to act jointly?

A – *If appointed jointly, they have to agree on every decision before any action can be taken, and a situation may arise where they disagree on your care. Perhaps you could consider naming one son your Medical Proxy for personal care, and give the other son authority to act in financial and legal matters by giving him Power of Attorney for Property.*

Q – I have named my sister as my Medical Proxy because she is my only relative. What if she goes against the wishes I have expressed in my directive and makes other decisions on my health care?

A – If your health care practitioner (or any other concerned person) believes that your sister is failing to comply with your stated wishes, and that her actions are likely to cause harm to your physical or mental health, a written complaint can be lodged with the Office of the Minister of Health who will investigate the complaint and who may then appoint another Medical Proxy.

Appendix III

Factsheet for Medical Professionals Practising in South Africa

This factsheet by the Medical Protection Society Limited provides only a general overview of the topic and should not be relied upon as definitive guidance. *Advice correct as of March 2012*

Living wills/Advance directives: An advance directive is a statement or instruction given by a competent adult in anticipation of when a patient may lack capacity to make healthcare decisions. Such statements usually take the form of advance refusal of specified treatments, but may also contain information about the patient's values and beliefs, and are generally referred to as living wills. This factsheet outlines the main points to be aware of when a patient has advance directives in place.

Assessing capacity: From an ethical perspective, for an advance directive to be valid, four conditions must be met:

- The patient must have issued the directives when they were aged 18 or over.
- You must be sure that the patient had the mental capacity to make their own medical decisions at the time of issuing the directives.
- A patient may only refuse consent to treatment if they have been fully informed about their condition and proposed treatment.
- You must be satisfied that the patient did not change his or her mind after issuing the directive.

If all four of these conditions are met, it is accepted – at least from an ethical point of view – that the advance directives must be followed. It is further accepted that the advance directives will also remain valid even when the patient later loses decisional capacity. Ensure that you see a copy of the original living will before proceeding with or withdrawing treatment.

Enduring powers of attorney: The dilemma

"Many older persons want to make provision for someone else to manage their property and affairs. Often the intention is to cater for when they are no longer capable of doing so for themselves. They then give such authority to a family member, attorney or financial adviser in the form of a power of attorney, thinking that the power of attorney will remain effective until they pass away.

The problem arises when the principal's mental capacity starts to diminish and he/she loses the capacity to act. South African common law determines that a power of attorney terminates once the principal becomes mentally incapacitated. In other words, when a principal is no longer able to perform the act in question himself, the agent can no longer do it for him. A validly concluded power of attorney therefore automatically lapses as soon as the principal loses the legal capacity to act.

The dilemma: the agent is suddenly left with no authority to act on behalf of the principal and the principal cannot act either since he/she is mentally incapacitated. If the agent continues to act on the void power of attorney, he exposes himself to personal liability for any losses suffered by a third party as a result of transactions arising from the void power of attorney.

In this instance an option would be to apply to court for the appointment of an administrator or a curator, depending on the circumstances. This involves costs (both the initial and running costs), takes time and makes the person's state of health and financial affairs public. Another alternative would be to set up a family trust, which itself takes time and could be overly complex.

The enduring power of attorney

Countries such as the UK, Canada, USA, New Zealand and Australia have already introduced enduring powers of attorney that remain in force despite the mental incapacity of the principal. The principal - while still mentally competent - executes a power of attorney which explicitly states that the power of attorney is to remain valid despite a decrease of capacity which the principal may experience in the future.

The possibility of introducing such a system in South Africa has been investigated by the South African Law Reform Commission. Recommendations were made in a report entitled "Assisted Decision-making: Adults with Impaired Decision-making Capacity" Discussion Paper 105 (January 2004)" which included a draft bill. It is, however, ten years later and the matter has yet to be taken further.

In light of the above it is clear that a power of attorney is of little or no value to someone who fears that their mental capacity is weakening or may be weakened in the future and who wants someone to act on their behalf if and when that situation arises. It is also debatable whether an enduring power of attorney will be accepted in our law considering our law of agency is based upon the principle that an agent cannot do that which his principal has no capacity to do himself.

South Africa desperately needs to cater for adults with impaired decision-making capacity - either by way of introducing new legislation which makes provision for assisted decision making in a simpler, more accessible form than our current curatorship system, or by making provision for a type of enduring power of attorney which is developed on the basis of our common law principles of agency."

The above section was extracted from this important article. For more, go here:
http://www.bizcommunity.com/Article/196/364/110658.html

Legal aspects: Advance directives – although ethically acceptable – are currently not recognised as legally enforceable instructions in terms of South African law. A patient's contemporaneous decision to refuse medical treatment and/or food and drink is valid in South African law. An advance directive, by definition, does not amount to a contemporaneous refusal of medical treatment – but rather, a prospective decision to refuse medical treatment.

Currently, there is no law in South Africa to validate the concept of a living will. A draft bill has been drawn up to change this after research carried out by the South African Law Commission found that there was a gap between the law and what is considered to be ethically acceptable among South African doctors. The draft bill, entitled "The End of Life Decisions Act", was drawn up in 1999 but has not yet been debated in Parliament.

Ethical guidance: The South African Medical Association (SAMA) and the Health Professions Council of South Africa (HPCSA) have both issued guidance stating that all patients have a right to refuse treatment. These guidelines also state that patients who have advance directives in place have constitutional rights to expect their living wills to be honoured. All doctors should make sure they are familiar with this guidance; see the Further Reading section for more information.

"*In cases where emergency treatment is necessary and you have not received evidence of a living will, you should provide the necessary treatment until you are notified of the directive*

If a patient has a terminal illness and wishes to draw up an advance directive, you should be aware of the following points:

- *Whilst it is the patient's responsibility to draft their own living will and inform their family members, you must be sure you have offered medical advice, counselling and support to the patient beforehand and on an on-going basis throughout treatment.*
- *Ensure old versions of the advance directive are destroyed if changes are made.*
- *Advance directives that are written in relation to a very general set of circumstances may not be valid if they fail to provide definitive instructions. Patients must be made aware of these restrictions before drafting their living wills.*
- *In cases where advance directives are either too specific or too vague, doctors must rely on their professional judgment to reach a decision.*
- *Written advance directives will be classed as representing the patient's wishes, if no other evidence is available to suggest they had later changed their mind.*

Summary: *In cases where emergency treatment is necessary and you have not received evidence of a living will, you should provide the necessary treatment until you are notified of the directive. Doctors who are not prepared to honour an advance directive must inform the patient of their views, and arrange for another doctor to resume care of the patient.*

Above all, remember that your overriding obligation is to act in the patient's best interests and to provide treatment and relieve suffering wherever possible. Doctors are advised to contact MPS for advice if they are unsure how to treat a patient who has advance directives in place."

http://www.medicalprotection.org/southafrica/factsheets/living-wills-advance-directives

HPCSA
Health Professions Council of South Africa

And finally, a very necessary read is Booklet 12 – 'Guidelines for the Withholding and Withdrawing of Treatment' by the Health Professions Council of South Africa. A copy can be downloaded here: http://www.hpcsa.co.za/downloads/conduct_ethics/rules/generic_ethical_rules/booklet_12_guidelines_withholding_and_withdrawing_treatment.pdf or you can write to lee@dignitysa.org or PO Box 927, Cape Town, 8000.

About DignitySA

Our Mission

DignitySA is a member-based registered charity (097-936-NPO). Our mission is to:

- Ensure all South Africans have free access to an Advance Directive
- promote palliative care and pain management as important elements of compassionate care and support,
- ensure health care professionals are trained on how to talk to patients about end-of-life choices,
- encourage end-of-life discussions between family members and loved ones,
- improve quality of dying and
- expand end of life options

Funding

We are funded by tax-deductible donations and memberships and receive no government funding. It is our intention to provide this Advance Directive for free to all South Africans. Providing it free, online, is the easy part. What we do need, however, is to raise sufficient ongoing funds to enable us to print it for people who do not have an online presence, which includes the majority of our Elders and indeed, the majority of South Africans. Also, we require funds to have this important document translated into as many indigenous languages as possible and to train people to hold awareness workshops all over the country.

Should you wish to donate towards this worthy cause, our bank details are as follows:

Account name:	DignitySA
Bank:	ABSA
Account number:	9274459317
Account type:	Savings
Reference Line:	Your name + AD

Alternatively, you can remember us in your Will.

You can go to this link for more information https://dignitysouthafrica.org/leave-a-gift-in-your-will/

A hard copy follows the Wallet Card on the next page.

Contact Information

Contact : Lee Last
Telephone : 076 942 4477
Email : lee@dignitysa.org
Website : www.dignitysouthafrica.org

Wallet Card

This card lets healthcare workers know you have talked to your family about Advance Directives and provides them with contact names and numbers.

It is essential that your health care provider be made aware that you have executed an Advance Directive. Your treating physicians should be given a copy of the documents. The wallet card is one way to do this. Fill out the card, then cut it out and carry it with you at all times. It is recommended that the wallet card be printed on board or card (thicker than regular 80g paper).

To fold the card to fit in your wallet, fold on the dotted line with the words facing out.

ADVANCE DIRECTIVE	**I HAVE AN ADVANCE DIRECTIVE**	**OTHER COPIES ARE HELD BY:**
	My name:	Name:
	My ID#:	Phone #:
	My Doctor's name:	Name:
	Doctor's Phone #:	Phone #:
	MY PRIMARY MEDICAL PROXY:	**MY ALTERNATE MEDICAL PROXY:**
	Proxy's Name:	Proxy's Name:
	Phone #:	Phone #:

Dignity SA
097-936-NPO
14 Francis Road
Pinelands 7405
Cape Town, South Africa

CODICIL

RELATING TO A FIXED SUM IN MY ESTATE

I, the undersigned, (full names and surname) _____ _____ ID number: _____, wish to supplement my most recent existing Will dated _____, as follows:

In addition to the provision of my said Will, I hereby bequeath to **Dignity South Africa (DSA)** (097-936 NPO) the sum of (amount in numbers) R_____ (amount in words) _____ OR a percentage (in numbers) _____% (in words) _____ of my estate not otherwise disposed of in my said Will, for use by them for general purposes.

Signed at _____ on this _____ day of _____ 20_____ in the presence of my witnesses, present at the same time and signing in the presence of each other:

_____
Signature of Testator / Testatrix

1st Witness: (Mr/Mrs/Miss/Miss/Dr) _____ Address _____
Occupation _____

Witnessed on this _____ day of _____ 20____ _____
Signature of 1st Witness

2nd Witness: (Mr/Mrs/Miss/Miss/Dr) _____
Address _____
Occupation _____

Witnessed on this _____ day of _____ 20____ _____
Signature of 2nd Witness