



# Advanced Directives Presentation

Date: 20 October 2025

A photograph showing a young woman in a blue scrub top smiling and holding the hand of an elderly woman who is seated in a wheelchair. The elderly woman is laughing. The background is a bright, indoor setting.

## TODAY'S FOCUS:

- Dignity South Africa's Background
- Four Choices at the end-of-life
- What are Advanced Directives?
- Advance Directives in Dementia: Supporting Loved Ones
- Questions & Answers



## Dignity South Africa - Brief Background

# Our Mission at Dignity South Africa

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- Dignity South Africa was co-founded in 2011 by Profs Sean Davison & Willem Landman.
- A response to the growing call for legal and social change around end-of-life choices in South Africa.
- At Dignity South Africa, our mission is simple but deeply important: every person deserves to live and die with dignity.
- We believe that a diagnosis, whether dementia or any other life-limiting illness, should never strip someone of their autonomy.
- Our goal is to ensure that every person's wishes are known, respected, and honoured, even when they can no longer speak for themselves.
- This means empowering families, healthcare professionals, and policymakers to act with compassion, clarity, and respect for choice.
- Ultimately, dignity at the end of life isn't about hastening death, it's about honouring life, right to the very end.

# The Unique Challenge of Dementia

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- Dementia presents one of the most complex end-of-life challenges.
- As the illness progresses, a person gradually loses clarity, memory, and the ability to communicate or make informed choices.
- Families are often left trying to interpret what their loved one would have wanted — and those decisions can be heartbreakingly difficult.
- Without clear guidance or legal frameworks, relatives are torn between guilt, fear of doing the wrong thing, and their deep love for the person.
- It's not just a medical issue — it's emotional, ethical, and profoundly human.

# What is assisted dying?

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DignitySA has been at the forefront of advocacy for the rights of individuals to make autonomous medical decisions, including the right to choose medical assistance in dying.

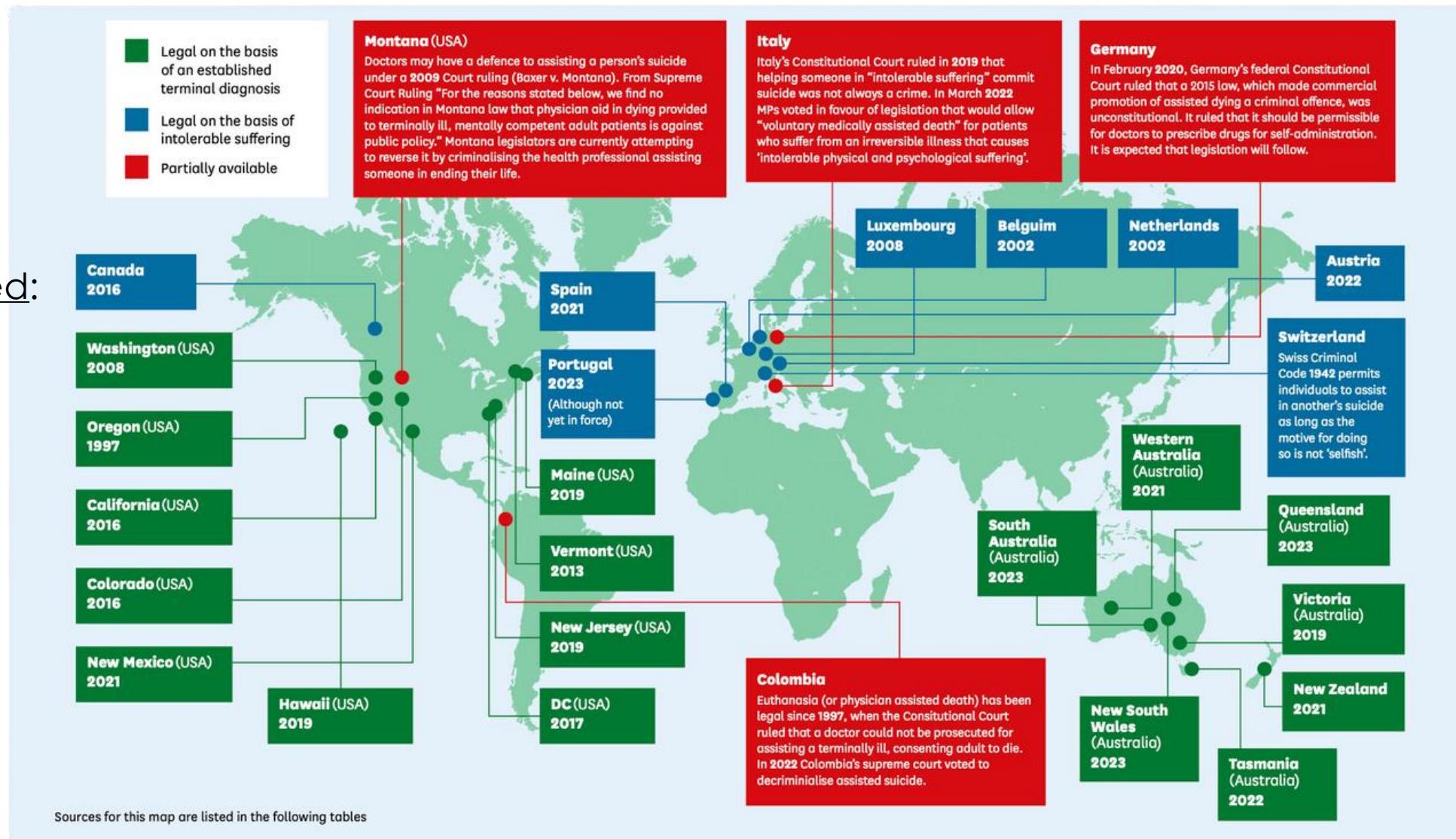
Two types:

- Self-administered death or dying. In this case, the doctor provides the patient with the means — often medication — and the patient takes it themselves when they're ready.
- Doctor-administered death or dying. That's when a doctor gives the patient a substance — usually through an injection.

# Jurisdictions where assisted dying is legal

## Recently legalized:

- Ecuador
- Peru
- Cuba
- Colombia
- Slovenia
- Isle of Man
- France



# What about South Africa?

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- Assisted dying is **Illegal** in South Africa, however...
- Court cases like **Stransham-Ford v Minister of Justice** have challenged this, citing constitutional rights such as dignity and freedom from cruel treatment.
- DignitySA is going to court to challenge the legal status of assisted dying and to get that right recognised in law.

# Constitutional Rights Supporting Assisted Dying

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- **Right to Human Dignity** (Section 10)
  - ✓ Everyone has the right to have their dignity respected and protected.
- **Right to Life** (Section 11)
  - ✓ Guarantees the right to live.
  - ✓ May also imply the freedom to choose how and when to die, especially in cases of unbearable suffering.
- **Freedom and Security of the Person** (Section 12). Includes the right to **bodily and psychological integrity**:
  - ✓ Making decisions about your own body.
  - ✓ Refusing medical treatment.
  - ✓ Choosing end-of-life options.

# The reality of dying and decision making

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- Death is an inevitable part of life.
- Modern medicine can prolong life but sometimes, it also prolongs suffering.
- End-of-life choices are often made in crisis.
- Many people endure **unbearable pain or loss of dignity** and simply want the right to choose when enough is enough.
- Their wishes are often ignored or unclear, leaving them powerless in their final moments.
- Even doctors face legal and ethical uncertainty, creating confusion at a time when compassion should lead the way.

# Four choices at end-of-life



- Palliative Care
- Withdrawing or withholding life sustaining treatment
- Assisted Dying and DignitySA's Constitutional Challenge
- Advanced Directives

# Focus areas at the end-of-life

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## Palliative Care

- Every South African deserves access to quality palliative care. We are building strategic partnerships within the palliative care sector to demonstrate our commitment to comprehensive end-of-life care.

## Withholding and Withdrawal of Life-sustaining Care

- Support patients' and families' right to refuse or discontinue life-sustaining medical treatments when they determine that the burdens outweigh the benefits.

## Assisted Dying

- We advocate for compassionate legal reform to give competent adults the choice of a medically assisted death. This is about autonomy, dignity, and mercy — not coercion or neglect.

## Advance Healthcare Directives

- Champion the legal recognition and enforcement of advance directives, ensuring that healthcare professionals honour patients' documented wishes regarding their end-of-life care, including decisions about life-sustaining treatment.



# What are Advanced Directives?

# Advanced Directives

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Two documents that outline your healthcare wishes.

- **A Living Will** - what you want (your decisions). Provides specific instructions to your doctors and healthcare providers.
- **A Durable Power of Attorney for Healthcare** - who will speak for you (your healthcare proxy).
- A **living will on its own is not legally binding**, doctors are not required to follow it.
- What carries legal authority is the **decision of your appointed healthcare proxy**, who communicates your wishes to the doctors.

# Advanced Directives

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- There is currently **no legislation** clarifying the legal basis for advance directives in South Africa.
- In 2018, DignitySA collaborated with parliamentary legal teams to draft an amendment to the National Health Act (61 of 2003) to legalise advance directives - stalled due to a new election cycle and COVID-19.
- Engagement with stakeholders across the healthcare spectrum reveals strong support for legislation from both medical professionals and the public.
- Advance directives are supported by **professional bodies** including South African Medical Association (**SAMA**) and Health Professions Council of South Africa (**HPCSA**).
- **DignitySA goal for 2025/26:** mobilise a multi-stakeholder alliance to lobby a sympathetic politician to resubmit the bill to parliament.

# Why should you have an Advanced Directive?

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- Ensures your treatment preferences are known during emergencies.
- Helps loved ones make informed decisions on your behalf.
- Prevents unwanted aggressive medical interventions.
- Allows for specific treatment preferences to be honoured.
- Reduces family conflicts during critical moments.
- Encourages dying at home rather than in a hospital.
- Promotes meaningful final moments with loved ones.
- Reflects your values and desires for end-of-life care.
- Discussing and planning for death can enhance life.

# Speak with Your Doctor

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- Discuss your health care desires directly with your doctor.
- Ensure your instructions are understood and more likely to be honoured.
- Doctors can help phrase requests clearly and answer questions.
- Identifies illogical or inconsistent treatment requests.
- Helps create a consistent and coherent directive.
- Informs you of any requests they cannot honour due to personal, moral, professional, or legal constraints.

# Speak with your family

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Discussing your health care wishes with family and friends is essential:

- Real-life situations may not align perfectly with written directives.
- Open conversations provide clarity and peace of mind.
- Loved ones can help interpret your wishes based on past discussions.
- Prevents confusion and potential legal disputes during incapacity.
- Encourages compassionate care and emotional support.



## What is a Living Will?

# Living Will

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A written document that specifies the types of medical treatments and life-sustaining measures you would want (or not want) if you are unable to communicate your wishes yourself.

When it takes effect:

- ONLY when **both** of these conditions are met:
  - ✓ You are **unable to communicate** your own wishes.
  - ✓ You are diagnosed with a **terminal condition** or are in a permanent state of unconsciousness (e.g. persistent vegetative state, end-stage dementia).

# Questions a Living Will Addresses

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It answers **critical questions**, such as:

- **CPR:** Do you want resuscitation if your heart stops?
- **Ventilator:** Do you want to be on a machine to breathe for you?
- **Tube Feeding:** Do you want artificial nutrition or hydration?
- **Pain Management:** Do you want aggressive pain relief, even if it may hasten death?
- **Organ Donation:** Do you wish to donate your organs or tissues?

# Benefits of a Living Will (Pros)

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- Upholds your Constitutional right to autonomy by giving power to the Health care proxy to state your wishes.
- Guides Healthcare Professionals.
- Reduces burden and guilt for family members.
- Provides clarity and prevents conflict.
- Peace of Mind.

# Important Limitations (Cons)

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## Key Limitations to Remember

- A **living will on its own is not legally binding**, doctors are not required to follow it.
- Possible Family Opposition.
- Emotional Difficulty in Making the Decisions.
- Requires proper drafting and discussion.
- It cannot predict or cover every possible future medical scenario, this is why it's **Important to pair with a Healthcare Power of Attorney**.



## Durable Power of Attorney for Healthcare

# What is a Durable Power of Attorney for Healthcare

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- Also known as a **Medical Power of Attorney or Healthcare Proxy**.
- It is a legal document where you designate a trusted person (your **"agent," "proxy,"** or **"surrogate"**) to make medical decisions on your behalf if you cannot.
- **Your Proxy is Your Advocate.**
- They speak for you based on the living will which contains your wishes.

# How It Works

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## **What It Does:**

- Appoints a person to be your voice.
- They consult with doctors, evaluate circumstances, and make decisions on your behalf.

## **When It Takes Effect:**

- Whenever you are incapacitated and unable to communicate.
- This includes temporary situations (e.g. under anaesthesia, in a temporary coma) and long-term ones.

# Decisions Your Healthcare Proxy Can Make

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Your healthcare proxy addresses situations like:

- **Interpreting Your Living Will** for unanticipated scenarios.
- **Choosing Between Treatments** (e.g. Medication vs. Surgery).
- **Approving or Refusing** medications, tests, or procedures.
- **Selecting Healthcare Facilities** or hiring home care.
- **Accessing Medical Records** on your behalf.

# Why is choosing a Healthcare Proxy more important than writing a Living Will

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- The most important step in your advance directives is naming your healthcare proxy.
- Your proxy's decisions are **legally binding**, not the living will alone.
- Make sure your proxy understands your wishes clearly so they can uphold your wishes if/when you're unable to speak for yourself.
- If you don't appoint a proxy, the law provides a **default order of decision-makers**:
  - ✓ Parents (unmarried)
  - ✓ Spouse (if married)
  - ✓ Children (if spouse is deceased)
  - ✓ Siblings (if no children)
  - ✓ Medical team discretion (in emergencies or when no family is reachable)

# Merits for selecting a Healthcare Proxy (Pros)

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- **Clarity & Advocacy:** Provides a single, trusted person to communicate with healthcare teams, reducing confusion and ensuring your values are represented.
- **Real-Time Decisions:** Your agent can respond to unanticipated medical situations and current facts.
- **Comprehensive Coverage:** Covers all medical decisions, not just end-of-life care.
- **Peace of Mind:** Ensures someone you trust is in charge, no matter what happens.

# Limitations to Consider (Cons)

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- **Agent Conflict:** Your chosen proxy may struggle to make emotionally difficult decisions or may not honour your wishes due to their own beliefs.
- **Unclear Wishes:** If you haven't discussed your values with your proxy, they may have to guess what you would want.
- **Country Laws:** Specific rules and laws must be properly executed to be valid.
- **Not a Solo Solution:** Best used **in combination with a Living Will.**

# Recommendations for Creating Valid Advance Directive

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- **Appoint your healthcare proxy:** your proxy's decisions are **legally binding** - not the living will alone.
- **Put It in Writing:** while oral directives are theoretically possible, a written document is essential for clarity and evidence.
- **Be Specific:** clearly describe the medical conditions and treatments you are referring to. Vague language can lead to misinterpretation.
- **Use Witnesses:** have the document signed by **two competent witnesses**.
- **Discuss Thoroughly:** have detailed conversations with your appointed healthcare proxy, your family, and your primary care doctor.
- **Distribute Copies:** copies to your proxy, your family, your lawyer, and your doctor. Keep the original in an easily accessible place.
- You can find the Healthcare Proxy Declaration Form on our website - [www.dignitysouthafrica.org](http://www.dignitysouthafrica.org)



# Advance Directives in Dementia: Supporting Loved Ones

# Why Advance Directives Matter in Dementia

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- Preserve autonomy before capacity fades.
- Families face heartbreakin choices without guidance.
- Protect against unwanted or harmful interventions.
- Supporting person-centred care (place of care, cultural or religious considerations, etc).
- Advance Directives are not just legal papers, but:
  - ✓ Acts of foresight
  - ✓ Expressions of love
  - ✓ Gifts of clarity for families

# **Signing a Living Will & Durable Power of Attorney with Dementia**

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## **Key Questions**

- When is it no longer acceptable to sign these documents?
- Does a dementia diagnosis immediately affect legal capacity?
- What stage of dementia prevents legal signing?

# Legal capacity requirements

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## **The person must understand:**

- What the document is
- What it does
- The consequences of signing
- Be able to communicate decisions clearly

# **Dementia & Legal Capacity**

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**Diagnosis alone does not mean incapacity**

- Early-stage dementia: often still legally competent.
- Advance request – request for assisted dying in countries where it is legal.

**Capacity is judged by ability to understand and decide**

- Not by diagnosis, but by cognitive function.

# When does Signing Becomes Invalid?

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## **When the person:**

- Cannot comprehend the nature of the document.
- Cannot make informed decisions.
- Cannot communicate their wishes.

# Important Considerations

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- Medical evaluation may be needed.
- Legal advice is strongly recommended.
- “Lucid intervals” may allow signing even with dementia.
- Provision could be made for a third proxy (a second alternative to the first) who would only assume power of attorney if both the first and second are either predeceased, or unwilling or unfit to act as proxy.

# The Power of Advance Directives

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## More Than a Legal Document

- An Advance Directive is an **act of foresight, compassion, and love**.
- It allows a person to speak for themselves when they no longer can.
- It gives families the priceless gift of **clarity and relief** during an immensely difficult time.



## Recap on Frequently Asked Questions

# Recap - FAQ & Answers

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## **Why do I need Advance Directives?**

- Accidents, strokes, dementia, or terminal illness can leave you unable to decide for yourself. These documents ensure your wishes are respected.

## **Who can make a Living Will or appoint a Healthcare Proxy?**

- Any adult of sound mind can do so, freely and voluntarily.

## **What's the difference between a Living Will and a Healthcare Proxy?**

- **Living Will** = You write down your instructions about treatment you do or don't want.
- **Healthcare Proxy** = You appoint someone you trust to decide on your behalf when you can't. It is strongly recommended you do both.

## **Who decides if I can no longer make decisions on my own?**

- Healthcare Proxy: they decide for you, based on your Living Will.
- Without either: family/doctors may decide, not always as you wish.

# Recap - FAQ & Answers

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## ***Does this mean doctors stop caring for me?***

- No, you will always get comfort care (pain relief and support). It only stops unwanted treatments.

## ***Is this the same as assisted dying?***

- No, assisted dying causes death. Advance Directives let nature take its course.

## ***Could I be forced to sign one?***

- Never, it's 100% voluntary.

## ***What if I change my mind?***

- You can update or cancel anytime while you're still capable.

## ***What if my family disagrees?***

- Your directive is legally binding through your Proxy, who is obligated to advocate for the instructions outlined in your living will. Doctors and family must respect them.

# Recap - FAQ & Answers

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## ***Do I need witnesses?***

- Yes. Both documents must be signed in front of **two independent witnesses** who:
  - ✓ Are over 18,
  - ✓ Witnesses must be independent. Your spouse, proxy, or anyone who could benefit from your estate cannot sign as a witness, to ensure your choices are free and voluntary.

## ***What if my doctor refuses to follow my Living Will?***

- You can request transfer to another doctor or hospital that will respect your legal rights.

## ***Do I need a lawyer to sign one?***

- No. The documents just need to be completed, signed, and properly witnessed. But you can get legal advice if you want reassurance.

# Conclusion

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- In South Africa, healthcare proxies are recognized under **common law** and supported by the **National Health Act**.
- Their authority is generally respected when the living will is clearly documented and combined with a Healthcare Proxy. However, advance directives are not yet widely integrated into routine medical practice.
- The responsibility often falls on the individual and their family to:
  - ✓ Create a clear and well-executed document.
  - ✓ Ensure all relevant parties are aware of it and understand it.
  - ✓ Be prepared to advocate for its enforcement with healthcare providers.
- It is always recommended to consult with a South African attorney who specializes in medical law or estate planning when drafting an advance directive.

# Advocating for Choice and Dignity at the End of Life

[www.dignitysouthafrica.org](http://www.dignitysouthafrica.org)

