

# *“Living Wills”*

*What Everyone 18 Years and Older Needs To Know  
But Didn't Know To Ask!!*

*Information Provided Conforms With Catholic Church Teaching*

# What We'll be Covering

- ***Advance Health Care Directives***
  - ***Form***—What They Are
    - Their **many names**
    - **How they've evolved**
    - *Durable **Medical** Power of Attorney*
  - ***Substance***—What they cover
- How About Them ***18-Year-Olds?***
  - ***HIPAA*** & Its Implications
- ***Medicare Provisions***
- ***Other*** End-of-Life Planning '***Stuff***'
- ***Resources***
- ***Questions?***

# The Evolution of “Living Wills”

***Living Will***

(1<sup>st</sup> Generation)



***Advance Directive***

(2<sup>nd</sup> Generation: Adds Durable Medical Power of Attorney)



***Advance Directive***

(3<sup>rd</sup> Generation: Focuses on values rather than on technical procedures)

# Why Living Wills??

- **Living Wills** were created in response to the increasing sophistication and prevalence of medical technology.
  - **Of U.S. deaths, 25%-55% occur in health care facilities.** Numerous studies have documented critical deficits in the medical care of the dying; it has been found to be unnecessarily prolonged, painful, expensive, and emotionally burdensome to both patients and their families.
  - Aggressive medical intervention leaves nearly two million Americans confined to nursing homes, and over **1.4 million Americans remain so medically frail as to survive only through the use of feeding tubes.** As many as **30,000 persons are kept alive in comatose and permanently vegetative states.**

# Why Living Wills??

- **Cost burdens to individuals and families are considerable.**
  - A national study found that: **“In 20% of cases, a family member had to quit work;” 31% lost “all or most savings” (even though 96% had insurance); and “20% reported loss of [their] major source of income.”** Yet, studies indicate that **70-95% of people would rather refuse aggressive medical treatment** than have their lives medically prolonged in incompetent or other poor prognosis states.
  - **As more and more Americans experienced the burdens and diminishing benefits of invasive and aggressive medical treatment in poor prognosis states**—either directly (themselves) or through a loved one—**pressure began to mount to devise ways to avoid the suffering and costs associated with treatments one did not want** in personally untenable situations.
- **The first formal response to mitigate these problems was the *Living Will*.**

# *Living Wills*

- **The *Living Will*** dates from 1969
  - **It draws from estate law**, by which an individual can control property affairs after death (i.e., when no longer available to speak for himself or herself) **and provides a way for an individual to express his or her health care desires when no longer able to express health care wishes.**
  - Because this form of “will” was to be used while an individual was still alive (but no longer able to make decisions) **it was dubbed the “*Living Will*.”**

# A *Living Will* Specified Treatment

- A ***Living Will*** provides specific directives about the **course of treatment** that is to be followed by health care providers and caregivers for the person who creates the document.
  - The ***Living Will*** is **used only** if the patient has become **unable to give informed consent or refusal due to incapacity**.
  - In some cases a ***Living Will*** may forbid the use of various kinds of burdensome medical treatment.
- **Specified treatment can be very specific or very general.**

# Desire for Services

- More specific *Living Wills* may include information regarding an individual's desire for services such as analgesia (pain relief), antibiotics, hydration, feeding, and the use of ventilators or cardiopulmonary resuscitation.
- However, studies have also shown that **adults are more likely to complete these documents if they are written in everyday language and less focused on technical treatments.**

## Support for Early *Living Wills*

- ***Living Wills* proved to be very popular**, and by 2007, 41% of Americans had completed a ***Living Will***. In response to public needs, state legislatures soon passed **laws in support of *Living Wills* in virtually every state in the union.**
- However, by the late 1980s public advocacy groups became aware that **many people remained unaware of *Living Wills* and even fewer actually completed them.** In part, this was seen as a failure of health care providers and medical organizations to promote and support the use of these documents.
- **In December 1991, *The Patient Self-Determination Act (PSDA)* went into effect** and required health care providers (primarily hospitals, nursing homes and home health agencies) **to give patients information about their rights to make *Living Wills* under state law.**

# Living Will ‘Deficiencies’

- Most **Living Wills** tended to be **limited in scope and often failed to fully address presenting problems and needs.**
  - Many **individuals wrote out their wishes in ways that conflicted with quality medical practice.**
  - **Interpreting Living Wills** done by doctors **following ‘hospital policies’** often did not conform to patient desires.
  - In the absence of meaningful information, **family and physician “guesswork” was found to be accurate only about 24% of the time.**
- Ultimately, it was determined that a **Living Will alone was insufficient** to address many important health care decisions.
- **This led to the development of “2<sup>nd</sup> generation” Living Wills: Advance Directives.**

# The Advance Directive

- The **Advance Directive** incorporated a **Durable Medical Power of Attorney** with the **Living Will**.
- These early **Advance Directives** allowed an individual to name someone—**an Agent**—to make health care decisions on their behalf if they should be rendered incapable of making their own wishes known.
- **Durable Medical Powers of Attorney** are sometimes also identified as **Health Care Proxy Appointment** documents.

# *Durable Medical Power of Attorney 'Points to Ponder'*

- A ***Durable Medical Power of Attorney*** can give the **Agent** the authority to make health-care decisions for the grantor, **up to and including terminating care and life support.**
  - The grantor can typically modify or restrict the powers of the agent to make end-of-life decisions.
- Depending upon the jurisdiction, a ***Durable Medical Power of Attorney*** may or may not appear with a ***Living Will*** in a single, physical ***Advance Directive***.

# Benefit of An Advance Directive

- The primary benefit of 2<sup>nd</sup> generation *Advance Directives* is that the Agent can make real-time decisions in actual circumstances, as opposed to *Living Wills* framed in hypothetical situations.
- The appointed Agent has, in essence, the same rights to request or refuse treatment that the individual would have if still capable of making and communicating health care decisions.
- The 2<sup>nd</sup> generation *Advance Directive* was heartily endorsed by the American public, and supporting legislation soon followed in virtually all states.
- *But it was soon found that 2<sup>nd</sup> generation Advance Directives had problems of their own.*

## 2<sup>nd</sup> Generation ‘Deficiencies’

- Primarily, individuals using the 2<sup>nd</sup> generation ***Advance Directive*** faced problems similar to those that handicapped *Living Wills*—knowing what to tell their Agent about their wishes in a meaningful way.
  - The ***Advance Directive*** was a marked improvement over the *Living Will* but a study comparing appointed Agent decisions on behalf of an incapacitated person, **who later recovered**, found that **Agents overall still only chose correctly 68% of the time because most of what appointed Agents were told was too vague for meaningful interpretation.**
- This continuing problem of only 68% accuracy, even with appointed Agents, led to the development of “**3<sup>rd</sup> generation” *Advance Directives*.**

# 3<sup>rd</sup> Generation Advance Directives

- The goal of the 3<sup>rd</sup> generation *Advance Directive* was to move away from a focus on specific treatments and medical procedures to a focus on patient values and personal goals.
- Third generation *Advance Directives* were designed to contain enriched content to assist individuals and their Agents, families, and physicians to better understand and honor their wishes.
- The persistent challenge of 3<sup>rd</sup> generation values-based *Advance Directives* remains how best to link patient values and goals with medical care wishes.

## 3<sup>rd</sup> Generation Advance Directive 'Versions'

- The first of the third-generation **Advance Directives** was the **Values History** which is a “**two-part Advance Directive** document that elicits patient values about terminal medical care and therapy-specific directives.”
- The next widely recognized third generation **Advance Directive** is the **Medical Directive**, a six-page document that provides six case scenarios for advance medical decision-making.
- Perhaps the best known third generation **Advance Directive** is the **Five Wishes directive**. This document was developed in collaboration with multiple experts with funding from the Robert Wood Johnson foundation, and is distributed by the organization **Aging with Dignity**.\*

\* The *Five Wishes* directive was endorsed by Mother Teresa of the Sisters of Calcutta and by the Chief Justice of the Florida state supreme court. Two versions of the document meet statutory criteria in all 50 states.

# More 3<sup>rd</sup> Generation Advance Directive 'Versions'

- The ***Lifecare Advance Directive*** resulted from a review of more than 6,500 articles from medical, legal, sociological, and theological sources.
  - It focuses more on "health outcome states" than on rosters of medical treatments and legal jargon.
  - The primary criticism has been that it is very lengthy and tedious to complete.
- The ***Protective Medical Decisions Document (PMDD)*** provides general guidance to the Agent but **limits the Agent's authority to approve the direct and intentional ending of your life.**
  - Versions of the PMDD differ by state.

# Catholic Advance Directives

- **Catholic Advance Directives favor general, versus specific, guidance regarding end-of-life health care.**
- There are **numerous versions of Catholic Advance Directives** available online. Examples:
  - A ***Catholic Guide to End-of-Life Decisions*** developed by the ***National Catholic Bioethics Center***.
    - Provides a narrative covering the redemptive nature of suffering
    - Explains the difference between morally obligatory and optional means of conserving life
    - Addresses the role of advance medical directives and health care proxies
    - Describes the advocacy of euthanasia in America today
    - ***Includes an Advance Directive and Durable Medical Power of Attorney***
  - ***Living Will and Health Care Power of Attorney*** developed by the **Bishops of Pennsylvania**
    - Describes what you should know about *Health Care Directives* as a Catholic
    - ***Includes an Advance Directive and Durable Medical Power of Attorney***

# The 'Advance Directive' Bottom-Line

- The preponderance of experts recommend the completion of an **Advance Directive** document – especially one that includes both a **Living Will** and a **Durable Medical Power of Attorney**.
  - While most of the public continue to rely upon their state's standard **directive format**, research demonstrates that many of these documents are too jargon laden and vague, confusing, and incomplete to adequately capture an individual's wishes, and that **they focus too much on the needs of medical and legal practitioners to the exclusion of the needs of patients**.
- **To make the best choice, individuals should** consider reviewing several document styles to ensure that they **complete the document that best meets their personal needs**.
  - **Advance Directive documents are increasingly available online.**

# General or Detailed Advance Directive?

- **General**
  - Gives agent greatest flexibility in addressing treatment
  - May not cover everything that may come up
  - Puts a greater ‘decision burden’ on agent
- **Detailed**
  - May limit agent’s choices (but agent can digress from instructions if deemed appropriate)
  - Gives agent more information to consider when making health care decisions

# Have the best of both worlds!!

- Select an ***Advance Directive*** that gives **general guidance** to your Agent.
- Provide your Agent with **more detailed information elsewhere** to help him or her make decisions if that time ever comes.

# What an *Advance Directive* Can Address\*

- Pain
- Tests
- Life Support
- Comfort
- Physical Treatment
- What Loved Ones Should Know
- Catholic Considerations

\*Adapted from *Five Wishes Advance Directive*

# Pain / Tests

- **Pain**

- Medicine for relief of pain

- Types acceptable / not acceptable

- How much (to point of drowsiness / sleep or not)

- **Tests**

- Invasive and/or noninvasive

# Life Support

- Any medical procedure, device, or medication to keep a person alive including:
  - **Help with breathing** (e.g., oxygen, respirator, ventilator)
  - **Food and water** supplied by medical device (e.g., tube feeding)
  - **Cardiopulmonary resuscitation** (CPR) (e.g., manual CPR, defibrillator, epinephrine shots)
  - **Major surgery**
  - **Blood transfusions**
  - **Dialysis**
  - **Antibiotics**
  - **Anything else meant to keep a person alive**
- **In Coma** (Expected to awaken and recover / Not expected to awaken and/or recover) / **Not in Coma**
- **Brain damage** (Reversible / Not reversible) / **No brain damage**
- **Close to death** (Not expected to recover) / **Not close to death** (Expected to recover)
- **End Stage Condition** (Treatment is helping / Not helping)

# Comfort

- **Help for:**
  - Depression
  - Nausea
  - Shortness of breath
  - Hallucinations
- **Cool / moist cloth** on forehead for fever
- **Water to combat dryness** of lips / mouth
- **Warm baths / showers**
- **Staying fresh and clean**
- **Massage** with / without oils
- **Favorite music** played
- **Shaving, hair brushing, teeth brushing** (if not painful or discomforting)
- **Reading materials / Read aloud to** (e.g., Religious, novels, poems)

# Physical Treatment

- **Visitors**
  - Normal and Near death
    - **Visits by Priest**
    - **Sacraments** (Communion / Reconciliation / Anointing of the Sick)
    - **Praying** (Rosary / Divine Mercy Chaplet / Stations of the Cross)
- **Parishioners notified of illness**
- **Hand held / Talked to** (Responsive / Non-responsive)
- **Cared for with kindness & cheerfulness** (not sadness)
- **Pictures of loved ones** in room / near bed
- **Clothes & bed linens kept clean** (if incontinent)
- **Hospice Care**
- **Die at home if possible**

# What Loved Ones Should Know

- **My love for family**
- **Want forgiveness for hurts inflicted**
- **I forgive hurts received**
- **I do not fear death**—Death a new beginning
- **Family members **should** make peace with each other**
- **Remember me as I was when healthy**
- **Caregivers respect my wishes** even if not agree with them
- Look at **my dying as a time of personal growth** for everyone
- **Get counseling** if having trouble with my death
- **After my death**
  - Organ donation (Driver's license annotation)
  - How I want to be buried (in grave / mausoleum / cremation)
  - How I want to be remembered
  - Epitaph
  - Songs / Readings at funeral Mass / Memorial service / Grave site
  - Other wishes

# When Someone You Love Hits

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*They fall under the provisions of  
**HIPAA!!***

# The Health Insurance Portability and Accountability Act of 1996 (HIPAA)

**HIPAA** established, **for all patients 18 years of age and older**, a:

- **Privacy Rule**, which protects the privacy of individually identifiable health information;
- **Security Rule**, which sets national standards for the security of electronic protected health information;
- **Breach Notification Rule**, which requires covered entities and business associates to provide notification following a breach of unsecured protected health information;
- **Patient Safety Rule**, which protects the confidentiality of identifiable information being used to analyze patient safety events and improve patient safety.

# Individually Identifiable Health Information Privacy

- **Who is Covered?**
  - **Doctors, clinics, hospitals, dentists, nursing homes, pharmacies that transmit data electronically**
  - **Health Plans**
  - **Health Care Clearinghouses**

# HIPAA Implications

- **If your spouse is away** and you are incapacitated and admitted to a hospital, and you do not have an *Advance Directive* making your spouse your agent, *he or she may have difficulty getting information about your condition and/or may not be able to influence the type of care you receive.*
- **If you are a widow or widower** and you are incapacitated and admitted to a hospital, *a family member or other person you trust may have the same difficulties* unless you established an *Advance Directive* making them your agent.

# More HIPAA Implications

- **If your child is 18 years old**, is away at college, has an accident that incapacitates him or her, **and does not have an *Advance Directive* appointing you as their agent, the health care provider ministering to your child probably will not give you**, as a parent or guardian, **information concerning your child's condition or a say in the health care they are to be provided** if you contact the health care provider by phone (and perhaps not even if you are physically present)!

# HIPAA Provisions

- ***Patients 18 years of age and older*** have a right to decide **how** their health information is used or shared.
- In particular, patients have the right to decide **whether** their health information can be shared.
- **They do this by signing an authorization.**
- ***If a patient has not signed an authorization*** stating whether and how to share their health information, ***most health care providers will protect the information.***

# Getting “Agent” Information to a Health Care Provider

- **If you’re 18 years of age or older:** File an *Advance Directive* with all the Health Care Facilities you normally do business with
  - Doctors, clinics, hospitals, dentists, nursing homes, pharmacies that transmit data electronically
  - Health Plans
  - Health Care Clearinghouses
- **Keep a card in your wallet/purse stating:**
  - You have an *Advance Directive*
  - What hospital it is on file with
  - Who is your Agent with contact information
- **If you’re a *Designated Agent*:** Keep a copy of all *Advance Directives* that identify you as an ‘Agent’ in a secure place so you can find it quickly and ‘Fax’ it to any health care facility that may need it.

# Medicare Provisions and *Advance Directives*

- In the case of a patient who is incapacitated, **when an individual presents the hospital with an *Advance Directive* or similar document** executed by the patient and designating an individual to make medical decisions for the patient when incapacitated, then **the hospital must**, when presented with the document, **provide the required notice of its policies to the designated representative**.
- ***The explicit designation of a representative takes precedence over any non-designated relationship*** and continues throughout the patient's inpatient stay or outpatient visit, unless the patient ceases to be incapacitated and expressly withdraws the designation, either orally or in writing.\*

\* CMS Manual System , Pub. 100-07 State Operations Department of Health & Human Services (DHHS)

# 1<sup>st</sup> Year Under Medicare

- ***A Free "Welcome to Medicare" Preventive Visit:*** You can get this introductory visit only within the ***first 12 months you have Part B.*** This visit includes a review of your medical and social history related to your health and education and counseling about preventive services, including certain screenings, shots, and referrals for other care, if needed. It also includes:
  - Height, weight, and blood pressure measurements
  - A calculation of your body mass index
  - A simple vision test
  - A review of your potential risk for depression and your level of safety
  - ***An offer to talk with you about creating Advance Directives.***
  - A written plan letting you know which screenings, shots, and other preventive services you need.
  - Get details about coverage for screenings, shots, and other preventive services.
- ***This visit is covered one time. You don't need to have this visit to be covered for yearly "Wellness" visits.***

# Yearly Free Medicare Wellness Visits

- *If you've had Part B for longer than 12 months*, you can get this visit to develop or update a personalized prevention help plan to prevent disease and disability based on your current health and risk factors.
- Your provider will ask you to fill out a questionnaire, called a “*Health Risk Assessment*,” as part of this visit. Answering these questions can help you and your provider develop a personalized prevention plan to help you stay healthy and get the most out of your visit.
- *You can establish or update your Advance Directive information*

# Medicare or Not

- You can and should provide or update an ***Advance Directive*** for each individual in your family who is 18 years of age or older with each of your health care providers at any time!!

# Other End-of-Life Stuff

- Financial information / instructions
- Life Insurance Policy locations / instructions
- List of entities to be notified of death (e.g., military for pensions, companies paying pensions) / instructions
- Cemetery information
- Etc.

# Resources (1 of 2)

- ***A Catholic Guide to End-of-Life Decisions***, 2011—Encompasses an *Advance Directive* and *Health Care Proxy*. Online download cost: \$2.50  
<http://www.ncbcenter.org/page.aspx?pid=1204>
- ***FormSwift***: Free online *Advance Directive* and proxy forms:  
<https://formswift.com/builder.php?documentType=living-will&ses=d20d5430dd7dd719d7e1e029a4ec89cd&key=9726045>
- ***Five Wishes Online***, Encompasses *Advance Directive* and *Durable Medical Power of Attorney*: <https://fivewishesonline.agingwithdignity.org/> \$2.50 charge. Gives you 30 days to fill out the form online before printing.
- ***Lifecare Advance Directives***: Advance Directives of many types are located at this site and are available for purchase at a variety of prices and in a variety of forms:  
<https://www.lifecaredirectives.com/index.html>. The site also provides free access to state statutory *Advance Directives* including Pennsylvania's at:  
<https://www.lifecaredirectives.com/statutory.html>
- ***MyDirectives***, Free. Encompasses an *Advance Directive* and *Durable Medical Power of Attorney*, provides for audio and video statements:  
<https://secure.mydirectives.com/Onboarding>

# Resources (2 of 2)

- ***Patient Privacy—A Guide for Providers:***  
<http://www.medscape.org/viewarticle/781892?src=ocr>
- ***Pennsylvania Catholic Conference’s Advance Directive and Health Care Proxy:***  
Free downloadable PDF document: [www.pacatholic.org/wp-content/uploads/livingwill.pdf](http://www.pacatholic.org/wp-content/uploads/livingwill.pdf)
- ***Protective Medical Decisions Document*** is available from the *Patients Rights Council* for free (although a \$15.00 donation is suggested for each packet which contains three PMDDs, wallet cards, and other information. ) See:  
<http://www.patientsrightscouncil.org/site/advance-directive-protective-medical-decisions-document/> or phone: 800-958-5678
- ***Values History form:*** <https://www.google.com/search?q=Values+History+Directive&ie=utf-8&oe=utf-8&aq=t&rls=org.mozilla:en-US:official&client=firefox-a&channel=sb> (This is a Google response site at which you can find a listing for the *Values History Form*. Click on the ***Values History Form*** entry and the form will download as a PDF document.) The form does not include a *Health Care Power of Attorney*.