

UNDERSTANDING ADVANCE HEALTHCARE PLANNING

(A companion piece to the tri-fold pamphlet of the same name)

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CurePSP is committed to providing its constituents – patients, families, caregivers, and healthcare providers – with up-to-date educational information about topics relevant to living with prime-of-life neurodegenerative diseases.

It is of utmost importance that patients *understand* the disease and its potential treatments, *decide* their wishes for future care – including end-of-life care – and *discuss* these wishes with their family.

The earlier in disease progression these topics are addressed, the better for everyone – patient, family, and healthcare providers. The benefits of Advance Planning are many-fold; for example: a comfort or freeing-up feeling in having decided one's plans for possible disease complications; diminishing of fears through the course of the disease; helping the family and the team to stay “on the same page” in their ability to honor and carry out the patient's wishes.

This article will help you to recognize possible late-stage treatment options for neurodegenerative disease, as well as to understand the various kinds of planning documents.

EDUCATION ABOUT ADVANCE DIRECTIVES:

MAKING THE CASE

A 1997 study in the *Annals of Internal Medicine* (Hoffmann et al.) found that most people do not communicate in advance to their families and health care providers their wishes about treatment. Research published in the July 2017 issue of *Health Affairs* demonstrates that that statement is still true. In fact, only one-third of adults in the United States have Advance Directives (AD's). Furthermore, people living with chronic illnesses were only slightly more likely than healthy individuals to express their wishes in written documents.

Research studies consistently report that receiving education about Advance Directives significantly results in increased completion of such documents. (*JAMA* 1994, *University of Massachusetts Amherst College of Nursing* 2013, *General Medicine* 2014, *Journal of Pain and Symptom Management* 2017, among others).

It is up to each individual to decide if and how they want to think about their medical destiny. Education is key to ensuring that medical-legal issues are discussed, understood, and acted upon.

MYTH AND FACT ABOUT ADVANCE DIRECTIVES

Myth: Federal Law requires that every person have Advance Directives.

Fact: The Federal Patient Self-Determination Act of 1991 obligates healthcare institutions and professionals to *ask* patients if they have Advance Directives and to *provide information and education* about Advance Directives.

Myth: Most seriously ill patients have discussed cardiopulmonary resuscitation (CPR) with their doctor.

Fact: Most patients have not discussed CPR with their physician. Yet, the vast majority wants to have this discussion.

Myth: An attorney is required in order to complete one's Advance Directives.

Fact: Legal forms are required, but the services of a lawyer are not. The conversation is best started with one's physician and closest family members or trusted person. An attorney can be helpful in drafting personalized documents.

Myth: Some states in the US do not recognize Advance Directives.

Fact: Advance Directives are recognized in all 50 states. However, states differ regarding requirements such as number of witness or necessity of a notary. Some states maintain registries that allow quick access by agents and healthcare providers.

Myth: Advance Directives should be kept in a safe deposit box with other important papers.

Fact: A copy of your AD's should be readily available at home. Patients should also give a copy to their physicians and proxy (agent). It is a good idea to make extra copies in the event you need to be admitted to the hospital.

Myth: With an Advance Directive in place, the person gives up control.

Fact: Drawing up an Advance Directive gives you the opportunity to decide, state, and put in writing the end-of-life care you want, thereby helping your agent to represent *your* choices when the time comes.

THE BASICS

So, what are Advance Healthcare Directives? They are documents designed to insure that a person's wishes – to accept or refuse treatments – are met through written directives. Healthcare institutions (hospitals, home health, nursing homes, etc.) are legally obligated to: 1) ask patients if they have Advance Directives, and 2) to provide information and education about Advance Directives. It is up to each one of us to decide, while we are well and capable, how we will want unexpected medical events to be handled. By exercising our freedom to decide for ourselves our fate or the course of actions, we greatly decrease the chances of an arbitrary exercise of outside authority in determining our futures. Our aims in having AD's is are to give us maximum control of our lives and our futures, and to provide peace of mind to our loved ones.

Making healthcare decisions involves trying to understand a lot of information that may be confusing, daunting, and scary. There are multiple issues to consider and a variety of documents to obtain, draw up, sign, and periodically review. The definitions and explanations below present an overview of the documents and will help you to decide which ones are pertinent for you. The Resources will guide you to more detailed information and "next steps."

I. VALUES HISTORY

Values History forms are designed to help individuals reflect upon their own personal value system before and while making health care decisions. Approaching Advance Directives from a values perspective enables people to make healthcare choices in line with their values. The intention of a Values History is not only to help an individual understand his or her own wishes regarding advance care-planning, but also to convey one's ethics, views, and principles to family members. In that spirit, values questions include topics such as your overarching attitude or philosophy toward life and health, your goals, what makes your life feel worthwhile, what you fear, what you enjoy, your current health and health challenges, your views about independence-dependence, your role in significant relationships, your spiritual or religious beliefs and how those affect your feelings about illness, your attitudes and relationships with your healthcare providers, and more. Examples of different Values forms include: *Values History*, from the University of New Mexico Center of Health Law and Ethics; the book *Ethical Wills: A Modern Treasury*, edited by Jack Riemer and Nathaniel Stampfer (Schocken Books); *Ethical Wills & How to Prepare Them* (same authors as previous listing); *Ethical Wills: Putting Your Values on Paper*, by Barry K. Baines MD.

II. RESUSCITATION ORDERS

In the event that one's heart ceases to beat or is in a life-threatening abnormal rhythm, an individual has the right to choose what, if any, type of resuscitative intervention he or she would accept.

Do Not Resuscitate (DNR) (Also called: Do Not Attempt Resuscitation (DNAR) and Allow Natural Death (AND))

These are doctor's orders instructing medical personnel, nursing and hospital staff, *not* to try to return your heart to a normal rhythm by any means: cardiopulmonary resuscitation (CPR), electric shocks (defibrillation), and/or medications. On the other hand, a doctor may specify in writing the specific means by which *you* would or would not want to be revived. In addition, Do Not Resuscitate orders mean that you refuse life-support measures.

These orders require the patient's consent and signature, 2 witnesses, a physician's written order and signature, and inclusion in the patient's medical record. If a hospitalized patient does not want CPR under any circumstances, the physician is obligated to write the DNR order, thereby permitting nursing staff and code teams to withhold CPR. In out-of-hospital situations, such as at one's home or in a dedicated hospice facility, many states require a specific out-of-hospital form to be completed and signed by the patient or patient's proxy and the physician.

Do Not Intubate (DNI)

This order instructs medical personnel of a nursing facility or hospital that the patient does not want to be put on a ventilator, or breathing machine, to prolong his life.

III. LIVING WILL

A Living Will allows one to put into writing his or her wishes about future medical treatment should one have a *terminal* condition (incurable, irreversible, and where death is imminent) and be unable to communicate. The Living Will outlines one's desire to withhold "heroic measures." It usually addresses resuscitation and life support; however, it may cover more preferences and interventions. For example, Living Wills can specify directions about particular death-delaying procedures one wants or does not want, such as: artificial life support, transfusions, dialysis. The key points to remember about Living Wills are: 1) They refer to a *terminal* condition; 2) They do not designate a patient's spokesperson or proxy.

IV. DURABLE POWER OF ATTORNEY FOR HEALTHCARE (DPOA-HC)

The Durable Power of Attorney for Healthcare is a signed legal document that designates and authorizes an *agent* to carry out a person's healthcare and life-support wishes *at any time* in the future that one loses the ability to speak or to make one's own decisions. Every state in the United States has passed a state law recognizing Durable Power of Attorney for Healthcare. However, certain regulations may differ from state to state, e.g. whether a notary is required.

In addition to naming a healthcare agent, the person who is establishing a DPOA-HC also identifies alternate or successor agents who will serve – one at a time, and in listed order – if the original agent can no longer function in the role. A DPOA-HC can include instructions re: life-support measures, artificial nutrition (tube feeding and what type) and hydration (intravenous fluids), mechanical ventilation (tracheotomy), comfort care, if/when to end life-sustaining measures, CPR, anatomical organ gifts, and disposal of remains. It is crucial that anyone who is completing a DPOA-HC discusses his wishes with his chosen agent and successor(s). If those people indicate that they would not be comfortable expressing your personal wishes, then you need to choose another agent, or successor, as the case may be. If the time comes that your designated agent is unsure of the your wishes in a specific situation, that agent is *required* to speak in your “best interest.”

Remember to periodically review, update (if necessary), re-date, and initial the original document.

DPOA-HC's can be ended any time by informing your physician and agent of your decision, and by destroying the document; or by drafting, signing, and dating a new one.

V. PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST) OR MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT (MOLST)

POLST's are signed, practitioner's orders. The type of practitioners who can sign the POLST varies by state, and *may* include physician, advance practice registered nurse, nurse practitioner, and physician assistant. POLST's provide guidance about one's care near the end of life, and enable healthcare personnel to act immediately – and in line with your wishes – in an emergency. POLST's spell out what specific care should be administered or withheld *at the present moment in time* for a specific patient, as directed by a physician. Because these are signed, medical orders, they are “portable” in states where POLST programs have been legislatively determined. This means that all healthcare facilities and emergency service providers in the region have agreed to recognize and abide by the Orders, regardless of where the document was originally signed. POLST is particularly relevant to patients expected to transition from one health care setting to another. In short, the form acts as standing medical orders and applies to all health care personnel (e.g. EMT's, emergency room personnel, etc.) and in all settings (homes, assisted living facilities,

nursing homes, etc.). The form is completed after a careful discussion between the doctor and all parties involved. The form contains three sections: cardiopulmonary resuscitation, medical interventions, and artificially administered nutrition. The patient can choose no nutrition by tube, defined trial period of tube nutrition, or long-term artificial nutrition by tube. The POLST Paradigm is in effect in most states of the United States.

For more information, please see the POLST website: <http://polst.org>

VI. MENTAL HEALTH TREATMENT PREFERENCE

This type of directive asks you to state whether you would allow electroconvulsive treatment (ECT) or psychotropic medicine if you have a mental illness and are unable, at the time, to make these decisions for yourself. In addition, you can express whether you will accept admission to a mental health facility for up to a certain number of days (e.g. 17). You can name someone to speak for you. These orders are written and have an expiration (e.g. three years from signature date). They require witnesses. Mental Health Treatment Directives can be cancelled in writing as long as you are not receiving mental health treatment at the time of cancellation.

It is important to note that not all states have a Mental Health Treatment Advance Directive, and requirements may vary by state.

VII. GUARDIANSHIP

A guardian is a legally responsible individual who is court-appointed – on a limited-time or full-time basis – when an individual is not able to make decisions for him or herself *and* there are no advance directives and designated healthcare proxy, or no next of kin (commonly referred to as “surrogates”). Other instances that might necessitate a court-appointed guardian include families in which multiple first-degree relatives – even with mediation – cannot agree; or where a next of kin is clearly acting in his own self-interest and not that of the patient. Fortunately, formal guardianship is rarely required.

SPECIFICALLY PERTINENT TO PSP AND RELATED PRIME-OF-LIFE DISEASES

I. ARTIFICIAL NUTRITION AND HYDRATION (ANH)

Patients and families members often put off what they view as the morbid discussion of whether or not ANH should be used if swallowing problems and/or advanced dementia keep the patient from eating and drinking normally. Without the discussion, however, a crisis situation can develop. If the person with PSP is unable to make his/her wishes known, then it is left to the Durable Power of Attorney for Healthcare to decide whether or not to place a feeding tube.

If the person with PSP is competent and able to make care decisions, then the question of whether or not to accept ANH can be made based on individual circumstances and beliefs. But what if the patient is no longer able to make personal decisions and has not previously completed a Durable Power of Attorney for Health Care? The person acting as the health decision surrogate (spouse/partner, adult child, sibling, close friend) may struggle with the ANH decision and not have much time to think about it. The following information may be of help.

If ANH is being suggested because the patient is at risk for aspirating or has had a bout of aspiration pneumonia, it is important to know that the feeding tube will not prevent bacteria-laden saliva and nasal secretions from getting into the lungs and causing infection. In other words, patients could still die of pneumonia. Placing a feeding tube in a severely demented person can result in the patient trying to pull the tube out and needing to be physically restrained. This can worsen any agitation the person might have and may lead to the use of sedative medications. In the Cochrane review done in London, doctors searched for evidence that tube feeding improved the quality of life for people with advanced dementia but could not find any. They, in fact, found some evidence that tube feeding increased mortality and morbidity, and reduced quality of life.

Decision makers also worry that by not choosing ANH they are dooming the patient to a long and painful death. Reports from conscious dying patients indicate that thirst and appetite decrease naturally at the end of life. Conscious elderly patients slip quickly into a coma that is free of pain; observation of unconscious patients indicates that their dying process is quite peaceful. If the body is shutting down in preparation for death, artificial hydration – the process of giving intravenous fluids – can actually cause distress. The body is unable to rid itself of excess fluids at this time, and they can build up in the lungs making it hard to breath.

In an article that appeared in the *Journal of General Internal Medicine* the authors point out that we seem to have lost sight of the difference between a person who dies because he stops eating and drinking and one who stops eating and drinking because of the natural dying process. Hopefully in the future we will have clinical

studies that define more clearly when the use of ANH in advanced PSP adds quality as well as quantity to a patient's life and when ANH inhibits the natural process of dying.

II. SIGNS THAT THE END OF LIFE MAY BE NEAR

- More coughing and/or choking episodes
 - Significant speech, chewing, and/or swallowing difficulties, even inability to eat and drink
 - Rapid and significant weight loss
 - Infection which might require a hospitalization that the patient refuses
 - Serious falls that may cause head injuries or a major fracture
 - Loss of bladder or bowel control
 - Increased confusion or agitation
 - Immobility or bedbound status, presenting risk for blood clots and other complications
 - More sleep time and increased withdrawal in general
 - Incontinence and recurrent urinary tract infections, which may lead to sepsis
 - Reduced consciousness
 - A brief surge of alertness or function followed by a return to a lower level of consciousness
 - Periods of shallow or irregular breathing, or needing oxygen to breath comfortably
 - Changes in skin color and temperature
 - Changes in muscle function; jerks, loss of reflexes
 - Increased pain or difficulty controlling pain
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- Aspiration pneumonia is the most common cause of death in PSP.
 - The death is usually peaceful.

THE TAKE-AWAY MESSAGE: With this basic information in hand, we hope you will discuss and draw up your wishes in conversation with your family, your physician, and an experienced social worker or nurse. Doing so will provide you with control over decisions about your care even if you are unable to communicate in the future, and will provide your family or agent with valuable information about your care wishes

RESOURCES FOR FURTHER INFORMATION

American Bar Association

800/285-2221, www.americanbar.org

Family Caregiver Alliance

800/445-8106, info@caregiver.org, www.caregiver.org

National Academy of Elder Law Attorneys

520/881-4005, www.naela.org

National Hospice and Palliative Care Organization CaringInfo

800/658-8898, www.caringinfo.org DOWNLOAD YOUR STATE'S ADVANCE DIRECTIVE

National Institute on Aging Advance Care Planning

www.nia.nih.gov

National POLST Paradigm

202/780-8352, info@polst.org, www.polst.org

State Medical Societies in the US by State

www.emedevents.com and www.thedoctors.com

Values History c/o University of New Mexico Institute for Ethics

505/272-4566, hsc-ethics@salud.unm.edu, www.hscethics.unm.edu

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