

ADVANCE DIRECTIVES and Healthcare Decision-Making

Making healthcare decision in advance is challenging, both because future circumstances in which decisions may be necessary are unknown, and because healthcare language and issues in healthcare decision-making are unfamiliar. Yet we can prepare ourselves and our loved ones by talking about key issues and preferences.

A Glossary of Words and Phrases

When completing an Advance Directive and talking with people we want as surrogate decision-makers, clarification of some language and concepts may help us to better identify and discuss relevant personal preferences. Here are brief explanations of some key concepts. Talk about these with your loved ones. Ask your physician, nurse, social services representative or healthcare chaplain for further information.

“Advance decision-making” refers to decisions about healthcare alternatives to guide future care, including emergency treatment. Advance healthcare decisions are often somewhat general in scope, stating broad values, preferences and goals, but can be designed to address one’s specific medical and life circumstances.

“Advance Directive” and “Durable Power of Attorney for Healthcare (DPA-HC)” are verbal or written communications to doctors and others stating your preferences for healthcare decisions that may be required in the future. Other examples of written directives are a “Living Will” or “Directive to Physicians” which are usually general statements requesting “no heroics” or “comfort care only” in a terminal illness. An Advance Directive or Durable Power of Attorney legally authorizes a “SUBSTITUTE decision-maker” or “AGENT” to speak for you when you cannot speak for yourself, and usually includes statements about your healthcare preferences to guide your AGENT. It is very important to talk about your healthcare preferences with your AGENT in addition to any written statement. Your doctor(s) should be told about your Advance Directive, your healthcare preferences, and the name of your AGENT.

“Agent” or “Attorney-in-fact” is a person legally appointed through an ADVANCE DIRECTIVE or DURABLE POWER OF ATTORNEY FOR HEALTH CARE to make decisions for another person.

“Artificial nutrition and hydration” is nourishment provided by tubes placed into the stomach through the nose and throat (“nasogastric or NG tube”), or into the stomach or intestines through the skin (“PEG tube”), or directly into a vein (“IV”). “Hyper-alimentation” or “TPN” is delivery of specialized high-tech formulas that provide complete nutrition through an intravenous line directly into the bloodstream. Artificial nutrition and hydration do NOT include giving food or water by mouth with a cup, spoon, baby bottle, syringe, or drinking straw. A patient with no chance of recovery who cannot swallow may receive no desired benefit or comfort from tubes delivering artificial nutrition and hydration, which do involve some risks and may be seen as only delaying a natural death or prolonging suffering.

“Benefits and Burdens” of a treatment refer a particular treatment’s process and results for a patient judged in the light of that patient's values and desires. **“Benefits”** can include reversal of a disease process, recovery of a physical or mental function, or relief of pain.

“Burdens” can include risks, discomforts, and costs that must be borne to receive the treatment. It is possible that the same treatment, or treatment result, might be judged by one person as a “benefit” and by another as a “burden.” For example, a treatment with a low chance of success (“high risk” treatment) might be seen by one person as acceptable but by another as unacceptable, due to different personal values and needs. Even routine lab studies, blood transfusion and antibiotics may not provide benefits and may impose burdens.

“Best Interests Decision” is a decision made by a SUBSTITUTE decision-maker on behalf of a patient when there is no direct evidence of the patient's own preference. A treatment decision made “in the best interests” of another person should be based on whether there are more BENEFITS than BURDENS expected from the treatment in the presumed perspective of the patient. If the patient's values are known, for example through remembered conversations or an “ADVANCE DIRECTIVE,” then it is possible to make a “SUBSTITUTED” or “PROXY” decision.

“Capacity / Incapacity” refers to the ability of a person to make and communicate an informed choice (see “INFORMED CONSENT”) about a particular decision. A person's capacity to make healthcare decisions is specific to the need for a particular healthcare decision, and does not require, for example, the ability to balance a checkbook or name the current date or President. The capacity for communicating a decision usually does include an ability to give some reasons, based upon personal values and preferences, for the decision. However, the reasons do not have to convince others – giving reasons is simply evidence that

the choice has been carefully thought over in the light of one's personal values.

“Competence / Incompetence” are terms often used to mean the same as “capacity / incapacity.” “Incompetent,” however, is also a legal term meaning that a judge has made a legal determination that a person is incapable of making certain decisions and needs an appointed “conservator” to make those decisions. A “conservator of the person” can be given authority by a judge to make medical decisions.

“CPR” or “Cardio-Pulmonary Resuscitation” is an attempt to restore heartbeat or respiration when either of these vital functions “arrests” or stops. CPR can include any or all of several different methods: 1) chest compressions – by hand or machine, to circulate blood (this often breaks a patient’s ribs); 2) assisted breathing – through a tube in the windpipe and use of a respirator or ventilator to pump air into the lungs; 3) intravenous (IV) medicines – to stimulate heartbeat; 4) electrical shock – to stabilize irregular heartbeat. CPR was originally designed for unexpected cardiac arrest in otherwise healthy people, and is often ineffective for patients with already compromised health.

“Extraordinary / Ordinary” is an older ethical language no longer useful (now replaced by “BENEFITS / BURDENS”) in determining appropriate treatments. Many ‘ordinary’ treatments and diagnostic tests in modern healthcare may offer no BENEFIT and may increase or prolong suffering by interfering unnecessarily with natural dying.

“DNR”, “Do Not Resuscitate”, “DNAR”, “Do Not Attempt Resuscitation”, or “No Code” is a decision written by a physician not to use cardio-pulmonary resuscitation (CPR) if either heartbeat or

respiration stops. It is part of a shift of direction from curative care toward care to “Support Natural Death”. A “DNAR” decision is usually written in a hospital record as a doctor's order when death is accepted as the natural outcome of care or is imminent and the medical situation makes emergency resuscitation efforts unlikely to succeed in providing any lasting BENEFIT. (A “Pre-Hospital DNR Order” is a physician order recognized outside the hospital by emergency responders, so that ambulance transport of a patient to a hospital can be initiated without otherwise automatic CPR efforts in a medical emergency.) A DNAR order does not mean that other medical treatments will not be used when appropriate. It is even compatible with aggressive medical interventions, including surgery, when these offer hope of significant BENEFIT. However, a DNR order can be – and most often is – written along with additional orders such as “COMFORT OR PALLIATIVE CARE only” or “No intensive treatment” or “No hospitalization”.

“**Durable**” in regard to a Power of Attorney for Health Care means that the authority of the AGENT will “endure” beyond the time when the signer of the document (the “Principal”) can make and communicate his or her own choices. In fact, the AGENT usually only has decision-making authority when the Principal is unable to speak for himself or herself (though in an ADVANCE DIRECTIVE the AGENT can be given authority that begins immediately).

“**Futile treatments**” are, in the strictest use of the term, treatments known to medical science to be physiologically ineffective. Physicians should not offer, provide or continue futile treatments.

“**Informed consent**” is better called “informed decision-making” for it means either accepting or declining a particular treatment, after appropriate medical information and recommendation. In a life-threatening emergency consent to provide immediate treatment is presumed; otherwise, the patient’s consent is required by law for all medical treatments. The doctor's responsibility in informed decision-making is to provide to the patient (or SURROGATE / AGENT of the patient) understandable information about: (1) the facts of the healthcare situation, (2) the options or choices available, (3) the likely effects of each option, including the possibility of no treatment, and (4) a recommendation. The patient's (or AGENT's) responsibility is to get enough clarity about the healthcare situation and the doctor's recommendation to weigh the BENEFITS and BURDENS of each alternative in light of the patient's personal values, then to make and communicate a decision.

“**Life-prolonging procedure**” or “**life-support system**” is any medical means to sustain, restore, or supplant a vital bodily function (ie, one essential for life). A life-prolonging procedure may help a person survive an immediate threat in order to recover, may be a continuing necessity for survival, or may only artificially postpone the moment of death – or may simply be ineffective.

“**Limited time trial**” refers to a decision to try a particular treatment for a defined period of time, in order to test its effectiveness in reaching a defined goal. Defining a goal and time period for treatment is particularly helpful in making decisions about the prolonged use of life-support systems.

“**Palliative**” or “**comfort care**” relieves or prevents pain and discomfort, assures

hygiene, and supports personal dignity. Palliative care includes medications and also wholistic and patient initiatives such as exercises and lifestyle changes, relaxation skills, meditation, music and massage. Palliative care may be part of supporting natural death, or part of aggressive curative or rehabilitative care. Hospices are centers of expertise in palliative care.

“Persistent Vegetative State (PVS))” and “Brain Death” are not the same. Both are usually due to a lack of oxygen in the brain for a few minutes. “Brain death”, in which the entire brain including the brain stem is irreversibly dead, is a legal definition of “death” in most states. **PVS** is a condition in which the brain stem is alive, though the cerebral cortex is irreversibly dead. The brain stem controls many basic “vegetative” body functions, including regulation of heartbeat, blood pressure, body temperature, breathing and the sleep-wake cycle. PVS is sometimes called an “open eyes coma” because a “waking” (eyes open) state exists simultaneously with a permanent loss of any ability to think or intentionally respond to the outside world (“coma”). If nourishment is provided by tubes, and occasional infections are treated with antibiotics, a patient in PVS can continue for years or decades.

“Substituted” or “Proxy” decisions are decisions made by a **SUBSTITUTE DECISION-MAKER** based on wishes previously expressed by the patient through an **ADVANCE DIRECTIVE** and/or from conversations. When the patient's own wishes are unknown, decisions must be based on the “**BEST INTERESTS**” of the patient.

“Substitute” or “Surrogate” decision-maker is a person who makes decisions

on behalf of another. The substitute decision-maker might be an “**AGENT**” authorized by the patient either orally or by an **ADVANCE DIRECTIVE** or **DURABLE POWER OF ATTORNEY**, a “conservator” authorized by a judge, or can be someone selected informally. In the absence of a formally authorized substitute decision-maker, close family members, often collectively, act in this role.

“Terminal” condition is a situation caused by illness or injury that will result in death in a relatively short time, usually defined as six months or less. There is a significant ambiguity in the meaning of “terminal condition.” It may mean either that 1) death will result in spite of any life-prolonging treatments or 2) death will result if no life-prolonging treatments are provided. In the first meaning, a treatment could be called “futile” even though it might succeed in extending life for a short time. In the second meaning, a person might live in a “terminal condition” for years if life-sustaining interventions are received.

“Verbal Directives” are the patient’s spoken decisions during the course of healthcare. “Advance Verbal Directives” are decisions and statements of preferences such as are in an **ADVANCE DIRECTIVE**, provided verbally to healthcare personnel. A patient can verbally designate a **SURROGATE** or **AGENT** to make health care decisions by personally informing the primary care physician. This verbal designation is authoritative only during the course of treatment, illness, or stay in the hospital. It is always good to speak up on these matters, and then when convenient to write such preferences down in an **ADVANCE DIRECTIVE** so that they are effective into the future.

Some Themes and Issues related to Advance Healthcare Planning

that merit discussion with your “Agent” and loved ones, your physician, and possibly a written statement:

Your “Agent’s” advocacy for you:

“This is my life and death. I feel very strongly about keeping my dignity at the end of my life. I rely on you to advocate for and implement my perspectives and choices, even if you might make different choices for yourself. Please ask me for any clarification you need.”

“Benefits and Burdens” of treatments

Generally it is not helpful (or easy!) to make a list of specific treatments that you do not want—for example, “I don’t want tubes,” “I don’t want a respirator,” or “No heroics”. It is more helpful to think in terms of the goals and priorities you would use in making such decisions.

Most of us choose to accept or reject a specific treatment because it promises (or not) to provide something that we value. We submit to even painful and invasive procedures when they promise benefits important to us. Likewise, we may reject a treatments, even minor pain or inconvenience, if we expect no personal benefit.

Our values and goals help us clarify personally the “burdens” and “benefits” of various healthcare treatments. Here are some topics that tend to be important when making healthcare decisions, and are good to talk about.

- relief of pain
- ability to experience / enjoy relationships
- ability to engage in favorite activities
- ability to think
- ability to communicate
- suffering and anxiety of self and others
- reconciliation and tying up of loose ends
- dependence / independence
- financial cost
- ability to move about
- control of bodily functions
- privacy
- dignity and dignified dying
- religious values

Additional issues you may want to clarify:

Antibiotics / Pneumonia

fighting some infections / allowing some infections as an OK way to die:

pneumonia as an “old person’s friend”

Artificial food and fluids

various methods of “tube feeding”:

NG, PEG, TPN; IV fluids for hydration

Coma

”permanent” “long lasting”

”possibility” vs “likelihood” of recovery

Comfort Care / Palliative Care

potential side effect of pain medications:

depressing respiration and shortening life

CPR

rates of survival of resuscitation attempts

”down time” (ie, without oxygen to brain)

Home [EMS] DNAR Order

Dementia and Alzheimer's disease

Dialysis

Head / Brain Injuries

Home / Board & Care / Nursing home - SNF

Hospice

[Acute] Hospitalization

Intensive care / ICU

Limited time trials

for some efforts / treatments / interventions

Multi-system organ failure

“Natural death” and

“Support Natural Death” Orders

“No Interventional / Curative Treatment” orders:

”Intensity of Intervention Orders”— including:

Do Not Resuscitate (DNR)

Do Not Attempt Resuscitation (DNAR)

Do Not Intubate (DNI)

Do Not Defibrillate (DND)

Do Not Hospitalize (DNH)

No Intravenous Lines (NIL)

No Blood Draws (NBD)

No Feeding Tube (NFT)

No Vital Signs (NVS)

Prognosis / statistical chances / risks

PVS — Persistent Vegetative State

Quadriplegia / Paraplegia

spinal cord injuries

Quality of life and Sanctity of life

basic qualities of a life worth living

ultimate values and perspectives of faith

Respirator / Ventilator

artificial or supported breathing

Tough choices:

“Just because a condition can be treated doesn’t mean it should be. My choice is that if I develop a life threatening but treatable disease – say, pneumonia – while dying of something else, or suffering from a progressively devastating disease, I want no treatment of that secondary disease. For example, don’t use antibiotics to cure pneumonia when cancer or Parkinson's or dementia is slowly killing me, or stop dialysis if I have multi-system failure. I consider an infection or kidney failure to be an OK, even a preferable, way to die. And provide pain relief even it may hasten dying.”

EXAMPLES OF LETTERS THAT COULD BE ATTACHED TO AN ADVANCE DIRECTIVE

To my Kids and Grandkids,

Please note the date on this paper. I attended a workshop on end of life decisions and it has prompted me to get some things written down for you.

I feel strongly about quality of life-not only for me but for all of you too. The time may come when I am dependent on others for my physical care. I hope that you can feel good about hiring help if I need it.

I feel comfortable about Assisted Living facilities when I need it and will try to make sure that I choose the place that I wish to go and get myself on a waiting list so you won't have to cope with this decision. If I fail to do this, you may want the help of a Case Manager. You can get more information about this from Senior Services of our County.

Please stay emotionally close but don't put your lives on hold over a long period of time-you can't get those years back and it would make me feel good to know that you are living your lives to the fullest.

I am presently in my right mind but if I should get dementia or Alzheimer's or have a stroke or whatever, I may not be thinking clearly at all. Please remember what I'm saying now while I'm relatively lucid and don't listen to pleas to take me home to live with you, etc. I do not want to have this happen to us.

If I should have a major physical and mental assault such a major stroke or dementia or have a diagnosis of a terminal illness, I do not want my life prolonged. This includes the use of a respirator, tube feeding, IV fluids for hydration, dialysis, ICU care, etc. This also includes the more ordinary things like antibiotics for infections, radiation or surgery unless used to relieve pain. I do not want CPR performed to attempt to revive me at this point. I do want pain medication to relieve pain and discomfort and anxiety.

If I'm having respiratory problems, you may be asked to give special permission to give morphine, as it depresses respiration and may hasten death. If I have no reasonable expectation for recovery that includes a good quality of life i.e. control over bodily functions, mental acuity, mobility and freedom from severe pain, please give permission for enough morphine to keep me comfortable and know that I would welcome ending my life a little sooner and with less misery.

If I am eligible — ie, most likely have 6 months or less to live — please involve Hospice. They are there to support all of us through a dignified dying process. Be aware that nursing homes are not the same as Hospice. They have an onus to keep patients alive and are often not able to support dying in the same fashion. I belong to Compassion in Dying. They are in the phone book and can be helpful in finding resources.

I think of Alzheimer's a lot because of _____ whom we all knew. We talked a lot when after the diagnosis and it made me think things through too. If I have a diagnosis of Alzheimer's or any other irreversible dementia, please discontinue all diagnostic tests, and curative or preventive treatments- Continue only comfort care, and support my dignity as well as possible short of damaging your own independent lives. I do not want any procedures done to lengthen my life at this point. These include antibiotics and other medications, surgery or other treatment for prolonging my life. I do not want CPR performed if a catastrophic event occurs after I have this diagnosis. Unless they have discovered some miracle cure for Alzheimer's between now and the time this is relevant, I only want pain relief.

I am a member of the _____ Church. I would appreciate the support of the minister of my Church as well as others from the Church as they know the kind of support I would welcome. I hope you will find support and solace from people who share your faith and understanding.

As always, my family is the most important thing to me and I hope you will all continue to communicate with me and stay emotionally close. Know that I love you all.

Mom/Gramma/G

EXAMPLES OF LETTERS THAT COULD BE ATTACHED TO AN ADVANCE DIRECTIVE

To my Children,

I want you to understand what I want if some kind of illness or accident should happen. This information should help you and me.

_____, I have designated you as my “Agent” with Durable Power of Attorney for Healthcare decisions. _____ is listed also, as an alternate. Please involve your siblings in your decision process, but keep central in your considerations what I want and do not ultimately make choices just to please them.

This is my life and death. I feel very strongly about having dignity and comfort at the end of my life. With the paperwork I have done, legally the doctors are obligated to abide by my wishes, yet many times I have witnessed families that override these legalities. Please do not let this happen. _____ will be a valuable resource for you. She is my best friend and a Registered Nurse. We have discussed this at length and she knows more than anyone what my wishes are.

I would never want a situation like this to cause you to pull away from each other. Use this time to grow closer as a family.

Now for my wishes:

If I get a terminal illness and am no longer able to make my own choices, please be there. I want you all close. Involve Hospice as soon as possible. Keep me comfortable. Do not do any procedures that prolong my life. Keep me well medicated with pain medications, anti-anxiety and anti-nausea medications. If these medications hasten my death at this time it would be OK with me, indeed a blessing. At the very end, for your comfort, have suctioning available. Please turn off all other treatments such as oxygen, for they are not needed then.

If you are not comfortable giving the **pain medications** at the end, _____ would do what I need and want. Get help from people who will follow my wishes. Please involve **Hospice**, the earlier the better; they are invaluable.

I would enjoy music, massage and any healing touch. I need your touch. Do not be afraid, I will know you are there even if it seems I do not. Of everything I have done in my life, I am most proud of all of you.

I do want to have visits from the Chaplain at any hospital I am in. They provide a very special service. I encourage you to also utilize this service. They are people trained to listen and just be there for you in your time of need.

If I am injured in a motor vehicular crash or similar situation: Many times the doctors do not know for several days to a week what the prognosis is. In this case listen to them, be sure to have _____ involved!

If I have a high spinal cord injury, many times these are complete (the spinal cord is severed). The doctors may try to have you wait, but if the injury is complete stop all treatment right away. Even with an incomplete injury, at my age, the prognosis is poor. I DO NOT want to live as a quadriplegic. Use your judgment here, but know you can stop any treatment at any time, even to the point of discontinuing tube feedings, IV fluid and stopping all antibiotics.

If I have a head injury, this is a gray area. If there were a possibility I could recover and rehab to a point that I could be fairly independent I would want this. I don't mind ending up with some disability, as long as I can live in my own home, and enjoy all of you. If you decide to try for recovery and I do not progress well, I encourage you to stop all treatments at that time, including tube feedings, IV fluid and antibiotics. Involve Hospice and let me go.

Another complication that can occur with any illness, especially as I get older, is **multi-system organ failure**. This is my body's way of letting you know it has had enough. Discontinue all life supporting treatments at this time. Always keep in mind the pain medications, keep me comfortable, even if it hastens my death.

If I am diagnosed with **Alzheimer's Disease** or another progressive dementia: I want no treatment, no antibiotics, no prolonging of my life. Put me in a nursing home as soon as I need to be there for my safety and realize I won't know most of the time who or where I am.

Be proactive, be my advocate if I am in a hospital. Most staff mean well. Remember the squeaky wheel gets the oil. Be insistent, yet kind. You have a right to be with me. Most ICU's these days are better than they used to be about family involvement. You have a right to be there! Studies show that patients recover much better with a shorter hospital stay when family is involved with their care. Talk to anyone you have problems with, then with the Charge Nurse, the Nurse Supervisor and ultimately the Director of Nurses or Patient Care Services.

Know also that if one of you is unable to be there due an inability to handle the situation emotionally, be involved in other ways to support your siblings. I will try to have most of my affairs in order, but I am sure there will be plenty to do. This is an important time for all of you and you need to figure out the best way for you each individually to handle the situation.

I love you all very much and hope you understand my need to give you this information. Death is a natural part of the circle of life. I love the Earth and living in my body, but these were not designed to be permanent. Hopefully you will not need this information for years to come, as I look forward to being here, watching you as you continue to grow and to meeting new ones who you bring into our family.

I love you all so much!! Mom

WORDS AND PHRASES to help you write a statement in your **ADVANCE DIRECTIVE**

This is some ‘starter text’ you can ‘cut and paste’ and customize to your needs when developing an [optional] written statement in your Advance Directive

Choice To Prolong Life when benefits outweigh burdens, with specific illustrations / emphases / clarifications

I want life sustaining treatment(s) to be provided within the limits of generally accepted health care standards, as long as my agent determines the benefits outweigh the burdens of care.

- Some, but not all, of the benefits I want to be considered are: ... [*list benefits of care / treatment or condition / outcome / quality of life, from your point of view*]
- Some, but not all, of the burdens I want to be considered are: ... [*list burdens of care / treatment or condition / outcome / quality of life, from your point of view*]
- Some, but not all, specific situations in which I do not want my life to be prolonged are if I am ... [*list specific conditions; see examples below*]

Choice To Prolong Life, specifying some conditions / qualities of life as key to recognizing “benefits” of treatments

I want life sustaining treatment(s) to be provided and I want my life prolonged within the limits of generally accepted health care standards...

... **AS LONG AS** there is a reasonable possibility of maintaining my life ... [*or*] my abilities to ... recognize friends and relatives and enjoy their visits, including communicate my concerns and joys, and be able to tolerate transfers to and from bed and take care of needs like basic personal care and eating....

Choice To Prolong Life, with some exceptions (“burdens” / conditions / qualities of life) specified

I want life sustaining treatment(s) to be provided and I want my life prolonged within the limits of generally accepted health care standards...

... **AS LONG AS** there is a reasonable possibility of maintaining my life ... [*or*] maintaining / recovering my abilities to... [*as above*]

... **EXCEPT** that I do not want my life to be prolonged,
and I do not want any life-prolonging treatments to be provided or continued, if I am: terminally ill, and the application of life prolonging procedures would only artificially delay the moment of my death.
in a persistent vegetative state, or in the judgment of my physician unconscious or in a coma which is likely irreversible or permanent, or unlikely to recover my abilities to visit with family and friends, and take care of basic personal needs ... [*etc*]
unconscious for over {ONE / TWO / THREE/...} month(s), without likelihood of recovering consciousness and my abilities to ... [*see examples above*]
mentally incapacitated, unable to communicate with family or friends, and this condition is irreversible or degenerative .