

How To Be An Effective and Empathetic Healthcare Surrogate

A Q&A Guide for a Gift of Compassion

Richard B. Stuart DSW, ABPP, Professor Emeritus of Psychiatry,
University of Washington and Medical Staff, Swedish/Edmonds Hospital

Stephen Thielke MD, MS, MA, Professor of Psychiatry, University of Washington

Jacob Appel MD, JD, Professor of Psychiatry and Medical Education,
Icahn School of Med at Mount Sinai

Darrell Udd MDiv, MA, Coordinator, Health Care Surrogate Support Program,
Shoreline Unitarian Universalist Church

About the Authors

Richard B. Stuart has been committed to protecting patients' rights throughout his professional career. He has been a clinical psychologist for more than 50 years. He is Clinical Professor Emeritus in the Department of Psychiatry at the University of Washington. He is also a member of the Medical Staff of Swedish/Edmonds Hospital. For many years, he served on hospital ethics committees helping patients and families make decisions about treatment options for very ill patients. He also mediates when family members want to override an advance directive and helps providers choose a course of action when very sick patients have not expressed their wishes.

He is the author of more than 100 publications, is a past president of the Association for Behavioral and Cognitive Therapy, is a Diplomate in Family Therapy at the American Board of Professional Psychology, and is a fellow in two divisions of the American Psychological Association.

Stephen Thielke is a geriatric psychiatrist and professor of Psychiatry and Behavioral Sciences at the University of Washington. He has conducted research about dementia, medication safety, weight changes in later life, technologies for aging, and geriatric depression. He has mentored dozens of medical students, residents, and fellows. He treats older adults with serious behavioral and cognitive impairments, and directs an intensive outpatient program.

Jacob M. Appel is currently Professor of Psychiatry and Medical Education at the Icahn School of Medicine at Mount Sinai in New York City, where he is Director of Ethics Education in Psychiatry, Associate Director of the Academy for Medicine and the Humanities, and Medical Director of the Mental Health Clinic at the East Harlem Health Outreach Program. Jacob is the author of numerous professional publications in addition to five literary novels, ten short story collections, an essay collection, a cozy mystery, a thriller, two volumes of poems and a compendium of dilemmas in medical ethics. He is Vice President and Treasurer of the National Book Critics Circle, co-chair of the Group for the Advancement of Psychiatry's Committee on Psychiatry & Law, and a Councilor of the New York County Psychiatric Society and of the American Academy of Psychiatry & Law.

Darrell Udd served as minister in Presbyterian Churches in New York City, Washington, and Oregon. He has taught in the Comparative Religion Programs at the University of Washington and Seattle University. He is a long-time member of the Shoreline Unitarian Universalist Church in Shoreline, Washington.

6-Steps Advance Directive is a small non-profit organization. The material presented here is offered without charge and with no expressed or implied warranty of any kind. Users should independently verify the validity of any documents they create with the help of this material in the venue(s) in which they will be used.

Contact

6-Steps Living Will
P.O. Box 236
Edmonds, WA 98020

E: rbstuart88@gmail.com
W: www.6stepslivingwill.org

This work is licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License, see <http://creativecommons.org/licenses/by-nc-sa/4.0/>

Table of Contents

Topic	Page
What Are Surrogates?	5
What Does A Surrogate Do?	5
Why Is Surrogacy Important?	6
Who Would Want Or Need A Surrogate?	6
What Is Decision-Making Capacity?	6
When Do Patients Lose Decision-Making Capacity Enough To Require A Surrogate?	7
What Should Be Included In Surrogacy Agreements?	7
What Are The Limits Of Surrogacy?	8
Who Can Be A Surrogate?	8
What Are The Characteristics Of A Good Surrogate?	8
Why Is It Important To Have More Than One Surrogate?	9
How Do Surrogates Learn About The Patient's Preferences?	9
What Is Decentering And Why Is It Important?	11
What Must Surrogates Have Before They Act On Patients' Behalf?	11
What Should Surrogates Do When They Are Needed?	12
What Can Go Wrong When Surrogates Act?	13
What Are Some Of The Costs Of Surrogacy?	14
How Often Should Surrogates Check-In With Patients And Record Their Preferences?	15
Can Surrogates Resign?	15
How Can Surrogates Convey Their Actions To Patients' Significant Others?	15
Do Surrogates Need Training?	15

Appendices	
1 Durable Power of Attorney for Healthcare	
2 HIPAA Authorization for Use or Disclosure of Health Information	
3 Surrogates' Patient & Selft Discovery Guide	
4 Conditional Medical Orders	
5 Questions to Ask Your Healthcare Provider	

Let's begin...

THANK YOU! You are about to give a remarkable gift to a relative, a friend, or a stranger. When sick people lose the capacity to make informed decisions about the treatments they receive, they are at risk of getting more or less treatment than they want. That happens because, despite a commitment to respect patient autonomy, unless there is a compelling reason to do otherwise, American healthcare institutions are obligated to offer active treatment, or to withhold low value treatment that patients may nevertheless want. Advance directives or living wills serve this purpose, clarifying the individual's wishes for their providers. Nevertheless, even the most carefully created advance care planning documents may be useless unless someone calls them to the attention of healthcare providers. The only one who can accomplish this is a healthcare surrogate. Patients may thus lose their ability to control what is done to their bodies unless they have both a precise advance directive and adequate representation. Here are four examples of situations in which either or both are lacking. As a consequence, these patients are at risk of receiving, or being denied, treatments that could create suffering and either tragically prolong or shortened their lives.

Norma is 75, an only child, and a widow. Although her diabetes is well controlled, she realizes that it could cause problems in the future that could result in complications such as blindness and/or amputation of her feet. She has a living will in which she requests comfort- care only but has no one to represent her. After she is admitted to the hospital with sepsis, the providers who are taking care of her consider it medically necessary to keep her blood sugars in tight control, and they are considering amputation of her right foot due to neuropathy. She is delirious due to her sepsis and cannot participate in decision making with the surgeon. Because she does not have a surrogate to advocate for the scope of treatment she wants, she is at risk of undergoing exactly the type of treatment she fervently hoped to avoid.

Emma is a 40 year-old mother of three who is in a coma following a major heart attack. A devout Catholic who believes in miracles, her advance directive stipulates that she wants full aggressive treatment no matter what condition she is in. Providers believe that treating her actively has little likelihood of being beneficial and are inclined to offer comfort care only to ease her death. Continuing her life therefore depends upon the efforts of her surrogate to get what might be low yield, but not futile, intervention that would allow her to have what she considers a meaningful death.

Ben, aged 25, suffered a major hemorrhagic stroke and is in an induced coma. He wants to be allowed to die rather than being kept alive, unable to think clearly and move independently. He has no advance directive or DPOA. Absent a living will, the ICU will honor his parents' directions. His father believes that he would consider his current condition much worse than death so he would want no intervention that delays a natural death. However, his mother believes that he loves life in any form and would want to pursue every intervention that might restore even a modicum of functioning. His parents' arguments both prolong his suffering in a condition that he might or might not want to endure, and also sabotage what had been a lengthy happy marriage.

Sarah and John have been married for 35 years but have never discussed the kind of treatment they would want if critically ill. When John has a heart attack and becomes unconscious, Sarah does not interfere with the hospital's delivery of aggressive treatment. But she has no idea if this is what John wanted. After he dies, she is haunted for years with nightmares that alternate between his expressing anger that she let him suffer so long or sorrow that she let him go before he had a chance to fight for life.

Many people hear stories like this think “it can't happen to me.” But things like this happen many times, every day, to people least expect them. Please don't be one of these people. Plan now to increase the odds of your getting the kind of care you want when you are most vulnerable.

Only a third of Americans create advance directives and many of these documents are either incomplete, too vague to be useful, or unavailable when needed. In addition, an increasing number of people have no one to speak for them because their partners, other family members and friends have died or are inaccessible, they have lived alone, or they are homeless. It is an incomparable gift to become a surrogate who helps people to document their wishes clearly, and who represents them when they cannot speak for themselves. Surrogacy offers another important benefit: many who lack representation are lonely, and their isolation can have a profoundly negative effect on their health and well-being. Their resilience and sense of security and belonging can be greatly enhanced when someone listens to them and acts on their behalf.

To help you perform this vital role, we want to answer common questions about the “what?” and the “how?” of surrogacy. Although there is some overlap across jurisdictions in this country and around the world, there are many different state and national laws regarding surrogacy. The recommendations here are consistent with provisions in the Revised Code of the State of Washington. You can learn the specifics of the jurisdictions in which you are likely to receive treatment by contacting that venue's Department of Health.

What are surrogates?

Surrogates are individuals chosen by patients to represent their preferences when they cannot speak for themselves, because they have temporarily or permanently lost the capacity to make informed decisions about the treatment(s) that they are offered. Patients designate surrogates by granting them the status of Durable Power of Attorney for Healthcare (DPOA or DPOAH). This assignment must meet each jurisdiction's standards and must be witnessed. Depending on where it is created, it may need to be notarized. It is “durable” because it remains in effect after the patient has lost decision-making capacity. It can be revoked if the patient regains capacity and chooses to do so, or if the surrogate resigns.

Terminology may vary considerably across jurisdictions. “Surrogate” is the term used here for an appointed third-party decision-maker. In some venues, terms such as “health care proxy,” “health care agent” and “health care power of attorney” are used. Their meanings are generally the same. Some venues use the term “surrogate” only for a default decision-maker, usually a relative or friend, who makes decisions in the absence of an appointed agent. However, elsewhere, the term for this default decision-maker is “next of kin.” For the sake of clarity, this document will use “surrogate” for an agent appointed to make healthcare decisions. We will also use “patient” to refer to the person who appoints the surrogate. Although the people may not be patients when they create a DPOA, they will become patients when surrogates act on their behalf.

What does a surrogate do?

An effective surrogate:

- Helps patients clarify their values and goals about medical care;
- Expresses patients' values and goals when they cannot do so;
- Negotiates with providers for the requested care;
- Provides emotional support for patients, if desired; and
- Clarifies patients' values and goals to family and friends, if asked.

In our program, surrogacy is a free act of compassion and good will with no financial compensation. It is *pro bono* in the true meaning of the phrase – carried out for the good of others.

Why is surrogacy important?

Healthcare facilities are legally required to offer the standard of medical care. That typically means active interventions that have some promise of benefit. That expectation works well if this is the type and level of care that patients want. However, the standard often does not suffice for patients who want less or more care than the routine offerings. Family members and friends may also disrupt patients' efforts to get the scope of care they want, by promoting their own goals rather than respecting patients' choices. In fact, the requests of family members and friends are likely to be respected if they are the only advocates. In these and similar situations, providing representation is a key to protecting patients' autonomy.

It is surrogates' responsibility to make patients' preferences known so the treatment they receive concurs with their goals, rather than being determined by institutional protocols or the preferences of non-designated individuals.

Who would want or need a surrogate?

In order to increase their opportunity to get the type and degree of care they want, all adults can record their preferences in writing, in the form of an advance directive or living will. Yet having the best possible document is useless unless providers very carefully consider the documents, which often happens because a surrogate brings it to the attention of caregivers. Since no one can know for sure when illness or accident will occur, and therefore when they might lose decision-making capacity, *It is never too early, but often too late, to put preferences in writing and designate a well-qualified person to present them.* Everyone aged 18 or older should do both.

What is decision-making capacity?

Standards for decision-making capacity vary across jurisdictions. According to the most widely used standard, capacity is defined as the ability to make and communicate a *particular* decision at a given moment in time. This involves the abilities to:

- Articulate, in a factually accurate manner, the condition that warrants action;
- Know that a consequential decision must be made;
- Understand the proposed treatment alternatives; and
- Appreciate the likely impact of accepting or rejecting the recommendation, or of forgoing treatment.

Venues differ in the stringency with which answers to these questions are evaluated. Determining whether patients have reasonable approaches to their situation requires some subjectivity, and reference to social norms, but patients can have decisional capacity even when they articulate decisions that most other people would not make.

Patients who pass all these tests are deemed to have capacity to make that particular decision, regardless of their general mental status. In other words, the presence of psychiatric or medical diagnoses, or of unconventional beliefs, does not prohibit patients from making an informed decision about the focal

intervention being considered. Patients with dementia or other forms of mental illness may have trouble remembering recent events or have other adjustment problems, but they retain the capacity to make many decisions, so long as they understand the choice being presented and the likely consequences of accepting or rejecting it. Patients with dementia, however, often lack the ability to advocate for themselves when communicating with health care providers. So while they may have decisional capacity around certain decisions, they might be assumed to lack it in the absence of a surrogate.

It is presumed that patients have decisional capacity until proven otherwise. However, any interested party can challenge this assumption, including the surrogate.

Capacity evaluations can be performed by many health care professionals and do not require mental health specialists. Disputes about capacity assessments can often be resolved by referral to an institutional ethics committee. Surrogates may be asked to participate in capacity evaluations, drawing upon their prior knowledge of the patient's functioning, although the final determination must be made and documented by a professional.

It is important not to confuse capacity with "competency." This is a separate construct, determined by a court of law rather than a health care provider. It refers to a representative's legal ability to make a broad array of decisions.

When do patients lose decision-making capacity enough to require a surrogate?

Patients can lose capacity if they:

- Are in a minimally conscious state;
- Are conscious but with judgment seriously compromised by dementia or other significant cognitive impairment;
- Have an extremely low level of health literacy; or
- Experience emotions strong enough to undermine the executive functioning needed to make informed decision.

If these conditions are resolved, patients can regain the capacity to make their own decisions, if patients are afforded enough time to understand and reflect on decisions, such as through being reminded of the same facts several times, they may show increasing capacity.

To learn more about capacity evaluation see: Stuart, RB, Thielke, S (2018). [Protocol for the Assessment of Patients' Capacity to Make End-of-Life Decisions](#). Journal of the American Medical Directors Association. 2018;19(2):106-109

What should be included in surrogacy agreements?

There are many different durable power of attorney (DPOA) forms, some very complex, and others relatively simple like the one Appendix 1. Each names surrogates and roughly defines the scope of decisions that the surrogates are empowered to make on the patient's behalf. We recommend our form that asks patients to:

- Appoint both a primary and back-up surrogate or successor agent;
- Designate anyone whom they specifically do not want to participate in decision making;

- Decide how much leeway they want the surrogate to have;
- Designate those they would like their surrogate to consult with to resolve any uncertainties;
- Indicate whether they would like this power to extend after their death, e.g. for autopsy; and
- Attest that the patient holds the surrogate blameless for good faith efforts taken to obtain goal-concordant care for the patient.

This latter provision is extremely important because, without it, patients or more likely their significant others, might belatedly challenge the surrogates' good faith efforts if they become unhappy with the outcome of the treatment for some reason. This risk could have a chilling impact on surrogates' willingness to act.

In the State of Washington, a surrogacy document must be witnessed by two signers who are neither caregiver nor employee of a care-giving organization. In Washington, a DPOA does not require notarization. However, those planning out-of-state travel should have the document notarized so it complies with the requirements of other jurisdictions.

It is also important for patients to sign a HIPAA (Health Insurance Portability and Accountability Act) form, such as the one in Appendix 2. This gives surrogates access to the health information upon which their actions depend.

What are the limits of surrogacy?

Surrogates make recommendations only about health care, such as scope of treatment, acceptance or rejection of specific procedures, choice of providers, and selection of care-giving institutions. *Surrogates do not have authority to make decisions regarding any other matters, such as financial, spiritual, or social aspects of the patient's situation.* In areas of health care in which surrogates have the authority to act, their recommendations are intended to strongly influence decisions about which treatments are offered, terminated, or withheld.

Who can be a surrogate?

A wide range of people can be chosen as surrogates. Many people choose their partners, adult children, other relatives, or trusted friends. Venues vary in the restrictions that bar some people from being surrogates, and it is wise to consult the rules in the jurisdiction in which treatment might be offered. In the state of Washington, for example surrogates cannot be an employee of an institution in which the patient receives care, or anyone against whom the patient has a protection order. Other states prohibit physicians from serving, even if they are not treating the patient.

If patients cannot name someone to represent them, community groups may provide Good Samaritans who are willing to serve. We hope that many readers of this Guide will have the generosity to offer this invaluable help.

What are the characteristics of a good surrogate?

Surrogates should be able to:

- Be aware of their own values and preferences;
- Genuinely understand the patient's values and preferences;
- Respect patients' preferences if they differ from what the surrogates would choose for themselves;

- Stay calm under pressure;
- Have at least a rudimentary understanding common treatment options, including the impact of offering or withholding recommended procedures such as cardiopulmonary resuscitation (CPR);
- Respect the patient's privacy;
- Respectfully negotiate with health care providers, family members, and friends;
- Be available when needed; and
- Have considered their own values and preferences around life-sustaining care, and have completed their own advance directive.

A close geographic proximity facilitates availability when needed, as well as increasing the opportunity to have in-person contact to create and regularly meet to update documents. All of these can be accomplished remotely, but in-person contacts greatly help to personalize the encounters.

Why is it important to have more than one surrogate?

Because surrogates are called upon to make rapid “in the moment” decisions, it is important for them to be available when needed. However, surrogates often have busy lives that limit their ability to respond quickly. Therefore, patients are well-advised to appoint one or more back-up surrogates or “successor agents” whose characteristics match those of the primary surrogate. If possible, the back-up(s) should participate in the creation of advance directives and in regular reviews in which the patient's preferences are updated. However, to minimize potential confusion, when critical care decisions are being made, ***only one surrogate should participate.***

How do surrogates learn the patient's preferences?

Surrogates learn patients' preferences through periodic discussions. The primary goals of these discussions are to help patients articulate the narratives of the scope of medical treatment they would like to receive. There is no fixed content for these discussions. Some begin when people are well, and barring the unexpected, their advance directives will not come into play for years if not decades. For them, dying and death are abstractions, not pressing realities. Others begin the process when they have been diagnosed with a major illness, at which time they may or may not be experiencing disquieting symptoms. Death may not be imminent, but it looms as an undeniable reality. And still other wait until they are in the advanced stages of a critical illness with death close at hand, and are likely to be experiencing more than a little pain and disability. The intensity, content, and tone of the discussions will vary as a function of which of these scenarios apply. In the first instance, the future trajectory is unknown and preferences will be more general. In the second and third scenarios, preferences can be more detailed because there is less uncertainty about the likely cause and timing of dying and death,

A common goal in each of the foregoing situations is for surrogates to understand the patients' values and goals. The “Golden Rule”— do unto others as you would have them do to you”— *does not apply*, because others may not want what you want. Therefore, the “Platinum Rule”— do unto others as they would have others them do unto them” applies. That requires focusing on patients' preferences. This is begun by establishing meaningful personal contact with patients they are meeting for the first time by revealing a little about themselves.

For example:

- "My name is...
- I am a volunteer with the, e.g., Shoreline Unitarian Universalist Church Surrogate Support Group
- I am not a healthcare professional — or I have been a XXX for YYY years
- I am committed to helping people obtain the type of care they want.
- I would like to begin by learning about who you are and what you would like."

Then ask questions that allow you to get to know the patient as a unique individual. Please remember that people define words like autonomy differently and find different meanings in concepts like "pain" and "disability. Therefore, it is important to ask about the patient's use of core terms rather than assuming that surrogate and patient view them similarly. As can be seen in the Surrogate's Patient and Self Discovery Guide (Appendix 3), one can begin by asking:

- How the patient wants to be known to others, i.e. attributes, historical experiences, and key relationships that the patient chooses as self-identifiers;
- The patient's values, including whether they wish to live as long as possible, or to die with comfort and dignity even if that means a shorter life;
- Whether the patient feels that there is still important work to do;
- The patient's spiritual beliefs and their impact on health care decisions;
- The patient's preferences regarding the management of pain;
- The patient's wishes with regard to privacy, autonomy, burden on the family, and the cost of care; and
- The possible impact of how they die on the way that they would like to be remembered.

Becoming known and accepted by another person can help to decrease a lonely patient's feelings of isolation and helps to build a strong, trusting foundation for the essential collaborative relationship.

Next, everyone who appoints a surrogate should also have created a living will that expresses their values and reasoning. The attached Conditional Medical Orders form (Appendix 4) is a one-page summary of patients' preferences that is signed by both patients and a health care provider who has the authority to enter orders in patients' medical records. This last step is crucial because it increases the likelihood that caregivers will be aware of their patient's preferences and their legal responsibility to honor them.

For surrogates to help patients complete a CMO, it is important to review the logic of Conditional Orders, as discussed in the following publication: Stuart RB, Birchfield G, Little, TE, Wetstone S, McDermott J. [Use of conditional medical orders to minimize moral, ethical, and legal risk in critical care](#). *Journal of Healthcare Risk Management*. 2021;1-10.

Reviewing patients' Final Statements that articulate their values and goals augments understanding their perspectives.

In addition, patients should share, information about their current health conditions and ongoing treatments with their surrogates. This can be done most conveniently by giving them a regularly updated copy of the attached "Information to Give Your Provider" (Appendix 5). This offers surrogates some understanding of the possible trajectory of the patients' condition. It is also useful because patients who receive emergency critical care are often seen for the first time by providers who may not have access to their medical records. This deficit can be filled by surrogates who present this brief document to providers or articulate what it expresses.

What is decentering and why is it important?

Every person has a unique perspective, and surrogates must be careful not to impose their values and ideas on the patients they represent. That requires them to "center" their thinking on the patient, and to "decenter" from themselves. In order to crystallize important differences, surrogates can use the attached Discovery Guide (Appendix 3) to articulate their own preferences and differentiate them from those of the patients they represent in the following areas:

- Maintaining physical autonomy;
- Being pain free;
- Managing bodily functions;
- Cognitive alertness;
- Reducing caregiver burden;
- Sustaining social contact;
- Minimizing cost;
- Dying at home; and
- Other important values or wishes.

In order for the surrogate reliably to respect the patient's values and avoid superimposing their own, it is essential to identify and consider any differences.

What must surrogates have before they act on patients' behalf?

Before they can act on a patient's behalf, surrogates MUST HAVE TWO DOCUMENTS:

- A carefully crafted living will, or, better still, a completed and signed Conditional Medical Orders (CMO) document that outlines the specifics of the patient's preferences (Appendix 4); and
- A signed and witnessed DPOA form that identifies the surrogate by name and contains a hold-blameless clause for actions taken in good faith to help the patient obtain goal-concordant care.

Surrogates must keep these two documents in a safe, easily accessible place in order to support any of their recommendations that might be challenged.

What should surrogates do when they are needed?

Surrogates have at least three roles to play:

- If necessary, to help patients create advance care plans (e.g. CMO documents);
- Represent them when patients cannot speak for themselves; and
- Possibly help friends and family members understand the patient's values and preferences, and/or the circumstances of the patient's death.

Each of these can be a complex interaction. For example, the most familiar actions are recommendations about whether to start or stop life-sustaining medical treatments, such as resuscitation, artificial ventilation, and feeding or hydration by tube, and whether to initiate hospice service. These are often at least triadic discussions involving providers, patients, and surrogates, and possibly more if significant others participate. Keeping the focus on the core issue is critical in these discussions. *The issue is not whether the recommendations are the best possible actions, but rather whether the patient would have chosen to do what was recommended.*

It is helpful for the surrogate to know when the patient is about to receive emergency medical care and to inform providers that a CMO, another advance directive and/or a DPOA exist. Having copies of these documents readily available greatly facilitates the process and saves valuable time. Timing is very important because delayed intervention could result in either too much or too little care, in settings when several minutes may make a crucial difference in the patient's course. For example, if surrogates accompany patients to an emergency department, it is very helpful if they bring copies of the signed documents that may or may not be immediately recoverable in the patient's medical record.

Surrogates can respectfully begin collaborative shared-decision-making discussions with the provider by;

- Introducing themselves as the patient's surrogate;
- Inquiring: "May I share what I know about the patient's health care values, and remind you about their advance directive or CMO, and their "Information To Give To Your Provider"?"
- Asking what action is recommended, including:
 - its intended benefits and harms;
 - the consequences of not doing it; and
 - the possible benefits and harms of alternatives, if any.
- Discussing how well these actions concur with the patient's goals; and
- Declaring that it is the surrogate's understanding that, if the patient could speak now, they would accept or reject each of the recommended treatments.

What can go wrong when surrogates act?

When it functions as intended, surrogacy can greatly facilitate the delivery of goal-concordant care. But at least four types of challenging scenarios can arise.

First, as their illnesses develop, patients may rethink their preferences by wanting to try harder to delay dying or to escape from the rigors of declining health. It is of course their right to do so and surrogates can play a key role by asking them express their hopes and fears and fit them into the narratives of their lives as discovered in earlier discussions. This might lead to revising their CMO.

Second, surrogates might be inclined to superimpose their own preferences rather than proposing what the patient would want. This can lead to longer and more complex hospital stays and even higher mortality. To guard against this, surrogates should;

- Identify potential decision-making challenges;
- Imagine what they would do in these situations; and
- Contrast their own wishes with what the patient has asked them to do.

This should help surrogates identify ways in which their preferences agree or conflict with the wishes of the patient, so they can recognize and decenter their own views when representing the patient.

Problems also arise if:

- Surrogates overreact emotionally and do not think clearly during crises;
- Attempt to dictate treatment strategies about which providers are the experts; or
- Request tests or other procedures that may not be useful because they feel compelled to "do something."

Anticipating these situations and rehearsing, visualizing, and practicing the most helpful responses, can facilitate making better decisions at times of crisis. For example, in order to address these risks, surrogates can:

- Recognize that they may have strong or catastrophic reactions, and imagine ways of approaching crises more rationally;
- Apply skills such as mindful relaxation or meditation before acting as a surrogate;
- Practice approaching providers as collaborators making shared decisions rather than adversaries when trying to choose the best treatment options;
- Ask whether additional testing or procedures would be helpful, or possibly duplicate or complicate current information; and
- Ask open-ended rather than pointed questions and adopt realistic rather than naïvely optimistic expectations.

Calm, respectful, well-planned interaction is a key to high quality surrogacy.

Third, some providers may believe that they, rather than their patients, know what is in their patients' best interests. They may be motivated by a deep belief that medicine is obliged to prolong life at all costs and experience moral distress if options are left untried. They may also have deeply held spiritual or existential beliefs that require or prohibit certain courses of action. Sad to say, a small minority may also be motivated by economic incentives. In each of these instances, it is important for surrogates to:

- Thank providers for sharing their perspective;
- Then remind them of the obligation to respect the patients' choices, even if they deem them to be unwise.

Fourth, the family or other interested parties may object. This can be motivated by their now knowing the facts, not being aware of the patient's preferences due to lack of contact, the belief that they should be the decision makers, or the desire to settle longstanding social or economic scores. Any of these can lead to opposition to honoring the patients' wishes. In these situations;

- Surrogates are not therapists and should make no effort to resolve any disputes;
- Instead, as with providers, they should express thanks for the perspective but state their only authority as the patient's agent is to try to promote care that concurs with the patient's values and goals.
- If this fails, surrogates can request consultation with the institution's ethics committee. Prompt actions are needed to protect patients from avoidable distress.

Fortunately, these situations are the exception rather than the norm, and by being prepared, surrogates can prevent them from derailing the orderly process of protecting patient autonomy.

As a final word for surrogates, patients, and providers: *Never assume that message sent is message received. ALWAYS, ask the listener to state in her or his own words what he understood the message to be.* Affirm correct understanding. To correct any misunderstandings, say "I may not have made myself clear. What I meant to say is...," restating your message. Repeat until message received matches the speaker's intent. This is the best way to avoid misunderstandings that threaten the delivery and receipt of goal-concurrent care.

What are some of the costs of surrogacy?

There should be no monetary fees for having or calling surrogates who are motivated by compassion and good will, but there can be emotional costs. Recommendations are often needed quickly and at inconvenient times, and may occur in high pressure situations with incomplete information and uncertain outcomes. Because of these unusual demands, many surrogates face the risk of post-decision remorse. This is reflected in the title of a recent *Journal of General Internal Medicine* article —"I don't want to be the one to say we should just let him die." However, it is important to remember that surrogates *do not in fact make strategic scope of treatment decisions: they merely express patients' choices. They are neither executioners nor saviors: instead, they are witnesses and reporters of the thoughtful choices that patients made when they created their advance directives.* At most, surrogates help inform tactical decisions as guided by their understanding of patients' stated best interests. *Surrogates are not responsible for outcomes, because their role is limited to asserting patients' preferences.* They have done their job if the patient is heard: it is the providers' job to deliver the requested treatment.

How often should surrogates check-in with patients and record their preferences?

Because patients' health conditions, prognoses, and values all change over time, creating an advance directive is not a single final step, but rather an ongoing process. Therefore, it is important for surrogates to check in with patients at least every four to six months to note any changes in health status, preferences, potential interventions, and providers or caregiving organizations. More frequent contacts may be needed when patients received intensive care for a serious condition.

An up-to-date surrogate will be a much stronger advocate. In addition, the contacts between patient and surrogate sustain a sense of connection and reduce patients' fear of having to face major health crises alone. This good feeling can be strengthened if the updates occur in groups through which patients and surrogates can share experiences and wisdom.

Can surrogates resign?

Surrogacy is a voluntary act from which surrogates can resign at any time. There are several valid reasons for doing so. For example, surrogates may:

- Become over-burdened with other issues;
- Lose their own decision-making capacity;
- Encounter fundamental disagreements with the patient whose changed values they are unwilling to support;
- Move out of the area; or
- Lose access to reliable channels of communication.

If any of these conditions occur, surrogate should notify the patient and providers of their decision to withdraw, and if possible, should continue to meet their responsibilities until the patient finds a suitable replacement.

How can surrogates convey their actions to patients' significant others?

Although patients may not choose family or significant others as surrogates, some of these people may nevertheless want to be participate in decision-making. Their input should be acknowledged, but they should be informed that surrogates are bound to follow patients' expressed preferences. Access to written and videotaped statements can greatly facilitate these discussions. Therefore, patients should be encouraged to preserve the signed original advance directives (e.g. CMO and DPOA), to make multiple copies of these documents, and to keep them prominently displayed so they can be easily found by anyone who needs them. Unfortunately, many people treat these documents as though they reveal private information that must be shielded from public view. Sequestering them in safe-deposit boxes or hiding them at the bottom of dresser drawers renders them essentially useless.

If family members appear to disagree with the patient's preferences, making and preserving a video clip in which patients express their preferences can be invaluable in overcoming opposition to critical care decisions, and in countering recriminations by significant others after the patient dies.

Do surrogates need training?

It may be a challenge to be an effective surrogate. More often than not, surrogacy goes smoothly. But challenges arise when quick actions is needed in high pressure settings that often use unfamiliar technical language. Being a surrogate is an experience unlike any other.

This Guide addresses only some of the many facets of the experience. To get up to speed, surrogates should begin by practicing with friends and colleagues, in order to develop sensitive ways to solicit patients' preferences, to demonstrate their understanding of them, and to continue the exchange until the patient feels fully understood. Role playing different types of interactions with providers is also helpful. For example, if a provider says something like "when my parent was in this condition, I made the following decision," it is best to respond, "thank you for that information, but the patient has stated that they want something else." Practicing several scenarios can help surrogates feel more secure and perform better when called to act. Sharing lessons learned with other surrogates can further enhance surrogates' invaluable contributions to patients' well-being.

A Final Note...

Thank you again for your precious service in ensuring that people receive the care that they would want, and do not receive the care they would decline. If you received this Guide from a health care organization, it might offer ongoing Surrogacy Workshops through which you can refresh your skills. If not, you could request training workshops. In addition, the facility that distributed the guide might warmly welcome your offer of surrogacy to others who are unrepresented. surrogates individually or in groups.

Appendix 1:

DURABLE POWER OF ATTORNEY FOR HEALTHCARE

Declaration made this _____ day of _____ (month), 20 _____

I, _____ having the capacity to make healthcare decisions, willfully and voluntarily wish to identify the person and/or people I have chosen to represent me if I temporarily or permanently lose the capacity to make healthcare decisions for myself. If I regain that capacity, I wish to reassert my own right to make decisions pertaining to the treatment that I receive.

1a. I appoint as my **PRIMARY Healthcare Representative**:

Name: _____

Address: _____

Email: _____ Phone(s): _____

Relationship to me: _____

1b. If the above named individual is not available to act on my behalf, I appoint the following person as my **ALTERNATE Healthcare Representative**:

Name: _____

Address: _____

Email: _____ Phone(s): _____

Relationship to me: _____

1c. If neither of the above named individuals is available to represent me, I authorize my healthcare providers to contact, in order, the following substitute decision-makers as approved for this purpose by the jurisdiction in which I am receiving care, i.e. my spouse or domestic partner, my adult children, my parents; and/or my adult brothers and sisters.

Name	Relationship
------	--------------

1. _____	_____
----------	-------

2. _____	_____
----------	-------

1d. I do not want the following people to participate in planning my end-of-life care.

Name	Relationship
------	--------------

1. _____	_____
----------	-------

2. _____	_____
----------	-------

2. I grant my representative(s) complete authority to make decisions consistent with my stated wishes with regard to starting, refusing, stopping, and/or removing all forms of medical, mechanical, and surgical intervention. I herewith hold my representative(s) blameless for good faith efforts to honor my preferences.

3. If my healthcare representative is unsure about what to decide, I want him or her to please *(initial ONE)*:

_____ ignore such doubts and act on my Living Will as written OR

_____ make the best decision he or she can in the face of uncertainty OR

_____ discuss the situation with my doctor, family members, and/or spiritual advisors named below, then use his or her best judgment and after considering their opinions.

Doctor(s) Name: _____

Family Member(s) Name: _____

Spiritual Advisor Name: _____

4. I Do _____ Do Not _____ (initial ONE) want this decision-making authority to extend to decisions that are made after my death with regard to autopsy, organ donation, and the handling of my remains.

5. I instruct my healthcare providers to release to my representative(s) any information about my medical condition, possible treatments, and prognosis pursuant to the attached HIPAA authorization for release of information.

6. This agreement supersedes and replaces any and all formerly executed Durable Power of Attorney Healthcare documents.

Sign only in the presence of witnesses:

Signed this _____ day in the month of _____, 20 _____

Signature: _____ Print name: _____

--

STATEMENT OF WITNESS #1

Under penalty of perjury under the laws of the State of _____ (State where document is signed)
on this day of _____ 20__ at _____ I stipulate that the following is true and correct:

- (1) ("Declarer") has been and is personally known to me.
- (2) I am **not** (a) related to Declarer by blood, marriage or adoption; (b) entitled to any portion of Declarer's estate upon Declarer's death under any will, or codicil, or any operation of law; (c) declarer's attending physician; (d) an employee of the attending physician or a health facility in which Declarer is a patient; or (e) a person who has a claim against any portion of the estate of Declarer upon Declarer's death.
- (3). I believe Declarer to be of sound mind and Declarer signed the foregoing Advance Directive willfully and voluntarily.

 Witness Signature

 Print Name

Address: _____

STATEMENT OF WITNESS #2

Under penalty of perjury under the laws of the State of _____ (State where document is signed)
on this day of _____ 20__ at _____ I stipulate that the following is true and correct:

- (1) ("Declarer") has been and is personally known to me.
- (2) I am **not** (a) related to Declarer by blood, marriage or adoption; (b) entitled to any portion of Declarer's estate upon Declarer's death under any will, or codicil, or any operation of law; (c) declarer's attending physician; (d) an employee of the attending physician or a health facility in which Declarer is a patient; or (e) a person who has a claim against any portion of the estate of Declarer upon Declarer's death.
- (3). I believe Declarer to be of sound mind and Declarer signed the foregoing Advance Directive willfully and voluntarily.

Witness Signature

Print Name

Address: _____

NOTARIZATION (Not required in many states, including Washington)

STATE of _____ County of _____

I certify that I know or have satisfactory evidence that _____ signed this document and acknowledged it to be his/her free and voluntary act for the uses and purposes mentioned in this document.

Dated this _____ of, _____ 20 _____ NOTARY PUBLIC in and for the State of _____
Residing at: _____ My commission expires on _____

11/11/2019

Appendix 2:

HIPAA AUTHORIZATION FOR USE OR DISCLOSURE OF HEALTH INFORMATION This form is for use when such authorization is required, and complies with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Standards. I. THE PATIENT. Patient's Name: _____ Date of Birth: _____ Social Security Number: _____ II. AUTHORIZATION. I authorize _____ ("Authorized Party") to use or disclose the following: (<i>check one</i>) ☐ All of my medical-related information. ☐ My medical information ONLY related to: _____. ☐ My medical-related information from _____ to _____. ☐ Other: _____. Hereinafter known as the "Medical Records." III. DISCLOSURE. The Authorized Party has my authorization to disclose Medical Records to: Name: _____ Address: _____ Phone: (____) ____ - _____ Fax: (____) ____ - _____ E-Mail: _____ IV. PURPOSE. The reason for this authorization is at my request (general). V. TERMINATION. This authorization will terminate: (<i>check one</i>) ☐ Upon sending a written revocation to the Authorized Party. ☐ On the following date: _____. ☐ Other: _____. VI. ACKNOWLEDGMENT OF RIGHTS. I understand that I have the right to revoke this authorization, in writing and at any time, except where uses or disclosures have already been made based upon my original permission. I might not be able to revoke this authorization if its purpose was to obtain insurance. I understand that uses and disclosures already made based upon my original permission cannot be taken back. I understand that it is possible that Medical Records and information used or disclosed with my permission may be re-disclosed by a recipient and no longer protected by the HIPAA Privacy Standards. I understand that treatment by any party may not be conditioned upon my signing of this authorization (unless treatment is sought only to create Medical Records for a third party or to take part in a research study) and that I may have the right to refuse to sign this authorization. I will receive a copy of this authorization after I have signed it. A copy of this authorization is as valid as the original. Signature of Patient: _____ Date: _____ Print Name: _____ <i>(IF THE PATIENT IS UNABLE TO SIGN, USE THE SIGNATURE AREA BELOW)</i> The patient is unable to sign due to: (<i>check one</i>) ☐ Being a Minor. Patient is _____ years old and considered a minor under state law. ☐ Being Incapacitated. Patient is incapacitated due to: _____. ☐ Other: _____. Signature of Representative: _____ Date: _____ Print Name: _____ Relationship to Patient: Parent Spouse Guardian Other: _____
--

Appendix 3:

Date: _____ Surrogate: _____ Patient: _____

Surrogates' Patient & Self Discovery Guide

Variable	Patient	Surrogate
Self descriptors		
Core values		
Quantity vs Quality of life?	Quantity Quality	Quantity Quality
Fulfilled life goals? Anything left to do?		
Spiritual beliefs? Impact of beliefs on health?		
Scope of care desired Explain limits	Full Limited Comfort	Full Limited Comfort
Please rate at least one item "low"— least important to you.		
Importance of pain control Self-care ability Cognitive functioning Burden on family Cost of care	Low 1-2--3-4-5 High Low 1-2--3-4-5 High Low 1-2--3-4-5 High Low 1-2--3-4-5 High Low 1-2--3-4-5 High	Low 1-2-3-4-5 High Low 1-2-3-4-5 High Low 1-2-3-4-5 High Low 1-2-3-4-5 High Low 1-2-3-4-5 High
Please choose between receiving each procedure Always, Maybe (limited) or Never		
CPR	Always Maybe Never	Always Maybe Never
Oxidation	Always Maybe Never	Always Maybe Never
ANH	Always Maybe Never	Always Maybe Never
Surgery	Always Maybe Never	Always Maybe Never
Antibiotics	Always Maybe Never	Always Maybe. Never
How much leeway re CMO?	Follow exactly Adjust If adjust, consult with?	Follow exactly Adjust If adjust, consult wit?
Die: Home Hospital Other If not home. explain	Home Hospital Other	Home Hospital Other
Notes (Use reverse if needed)		

APPENDIX 4:

Conditional Medical Orders

Patient _____ DOB ____/____/____

Surrogate Name, Phone, E-mail _____

In general, my goal is (Initial ONE)

_____ Live as long as possible, regardless of the quality of my life. _____ Prioritize quality of life over length of life.

Scope of treatment (Initial ONE)

- _____ Because I want to live as long as possible, I want all treatments, regardless of my quality of life.
_____ I am willing to try limited courses of treatments, as long as they might restore my capacity for a meaningful life, as defined in my personal statement.
_____ I want only comfort measures to relieve my suffering, but nothing to delay my death, particularly if I have lost capacity for a meaningful life as I defined in my personal statement.

Options for Conditional Resuscitation (CPR) Order (Initial ONE)

- _____ ACPR: ALWAYS attempt resuscitation if I have cardiopulmonary collapse.
_____ DNAR-X: DO NOT attempt resuscitation *except* in the event of cardiopulmonary collapse due to an obvious event that has reversible effects in the opinion of providers at the scene.
_____ DNAR: DO NOT attempt resuscitation if I suffer cardiopulmonary collapse, regardless of the cause.

Options for Conditional Intubate Orders (Initial ONE)

- _____ ALWAYS intubate by any means for any duration recommended.
_____ Intubate CONDITIONALLY, only if needed for resuscitation or the treatment of an acute event with reversible effects. Otherwise, use only non-invasive ventilation.
_____ DO NOT intubate if the sole purpose is to delay my death. Provide oxygen via noninvasive canula only for comfort.

Options for Conditional Artificial Nutrition and Hydration (ANH) Orders (Initial ONE)

- _____ Administer ANH by any method and for any duration as recommended.
_____ Administer nutrition and hydration conditionALLY, *only* for a *short time* to achieve a specific goal.
_____ DO NOT administer ANH. Provide nutrition and hydration orally only Accept my refusal of both.

Additional option that can be chosen along with conditional use or refusal of ANH

If I choose **VCED** (Voluntary Cessation of Eating and Drinking), and my providers will not support it, help me find a provider or institution that will support it. Initial: YES _____ NO _____

Medical Aid in Dying (MAID)

If my condition meets the legal requirements for MAID, and I want to use this service, and the provider(s) treating me, or the institution in which I am being treated, do not permit it, I wish to be transferred to a provider or institution that will honor this request. Initial: YES _____ NO _____

Leeway with Durable Power of Attorney for Health (DPOA) to designate a surrogate (Initial ONE)

I want my surrogate to follow my DPOA exactly as written Initial: YES _____ NO _____

I grant my surrogate permission to modify my requested treatment(s) at his/her discretion Initial: YES _____ NO _____

I hold blameless any provider who honors this order in good faith. Initial: YES _____ NO _____

Patient	Date
Surrogate	Date
Patient demonstrated sufficient decisional capacity: Provider initial: _____ Yes _____ No	
Patient demonstrated sufficient health literacy: Provider initial: _____ Yes _____ No	
(Circle profession: Physician, RN, ARNP, or PA-C	Date

Step 5

Make Yourself and Your Preferences Known

How to Have the Conversation

Questions to Ask Your Healthcare Provider

Your doctor and other healthcare providers cannot honor your requests for the kind of end-of-life care you want unless you tell them what you want. It is therefore important for you to bring copies of your Personal Statement, Advance Directive, and Durable Power of Attorney for Healthcare to the professionals who will provide your end-of-life care. This will give you a chance to have a very important conversation in which you make yourself and your preferences known.

You might begin the discussion by describing your ideas about how you would like to die and any religious or cultural beliefs that have shaped your point of view.

You can continue the discussion by asking your provider to state his or her understanding of what you want. Does he or she believe that you want?

_____ Full treatment, regardless of your condition, to prolong your life as long as possible.

_____ Limited treatment if it will slow the progress of your illness, shifting to comfort care if your illness continues to progress despite these efforts.

_____ Comfort care only if you have a terminal illness and your condition is one that you consider to be worse than death, allowing natural death.

You could then ask whether your providers are willing to help you in the following ways.

- Discuss treatment alternatives with you, including comfort care only, to help you understand the benefits and harms of each treatment alternative.
- Assure you that the providers and settings in which they will care for you have policies that permit them to offer the kind of care you request, e.g. do they have the capacity to offer full treatment or the willingness to offer comfort care only.
- Assure you that if they or the setting in which they work have policies that might prevent them from honoring your requests, they will assist you in transferring to other providers and/or settings where your requests will be honored.
- Assure you that a CMO (Conditional Medical Order), MOELI (Medical Orders for End of Life Intervention) or a POLST (Physician's Orders for Life Sustaining Treatment) or similar form (e.g. MOLST) will be prepared for you and entered into your medical record.

If it is important to you to have all the facts so you can make wise decisions about your healthcare, ask your providers to assure you that they will tell you the facts about your condition and the likely benefits and costs of each available treatment alternative. You may also ask that your doctor refer you to sources and sites where you can get more information about your illness and possible treatment.

Create a Summary Form

1. Complete the following page to provide much of the information that your providers will need in helping you and your healthcare representative make end-of-life plans.

NOTE: Since many doctors believe that they must do "everything possible" in order to avoid being sued for malpractice, this form also asks you to sign a statement declaring that you will ask your significant others not sue your doctor for following your wishes. This is not absolute protection for your doctor, but it is a commitment of good faith on your part.

2. Practice having the recommended conversation with a friend or family member.
3. When the information is complete, schedule an appointment with your critical care provider(s) to deliver this Step 5 and your 3-part Living Will so you can have this very important conversation.
4. Consider asking your healthcare representative and a significant other to join at least one meeting with your doctor so they have a chance to get to know each other a little under calm conditions. This will make it easier for them to collaborate with each other more efficiently if/when they must share decisions about how to handle a crisis. Make many copies of the next page. Update this form any time your medication or treatment changes. Bring the updated copy each time you meet with a new critical care provider and give copies to your healthcare representative and others who will speak for you when you cannot speak for yourself.

Summary of Important Information to Give to Your Provider

Please place this information in my medical chart.

1. Name: _____ Date of Birth: _____
2. I do have a Living Will dated: _____. Please add my Living Will to my medical record.
3. As a reminder, here are three things I consider to be important for you to know about me.
 - a) _____
 - b) _____
 - c) _____
4. My healthcare representative (surrogate) is:
Name: _____ Phone: _____ E-mail: _____
Address: _____
5. I am currently: _____ Married _____ Living with a Domestic Partner _____ Living with others _____ Living alone
Name of my spouse or partner: _____ Phone: _____ E-mail: _____
My partner's address (if not my surrogate): _____
(Initial ONE) _____ I Do _____ Do Not grant this person access to my medical records and discussion of my end-of-life care.
6. Listed below are the names and contact information of my alternate healthcare representatives and others I would like to have act on my behalf, in the order listed, if my representative is unavailable.

Name	Relationship	Mailing Address	Phone	E-Mail

Please list anyone that you specifically **DO NOT** want to participate in planning your end-of-life care.

I will hold you blameless for meeting community standards for the requested care, and have asked my representative and loved ones to do the same. (initial)

Your Signature: _____ Date: _____

On the next page please list all of the medications that you are **currently taking**.

This information can be a useful reminder for the providers you see regularly,
any new providers you consult, and first responders who answer calls.

Update this information as necessary to make sure it is complete and available in an emergency.

Date: _____

1. _____ 2. _____

3. _____ 4. _____

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

[illegible]