



THE HASTINGS CENTER
HELP WITH HARD QUESTIONS SERIES

PATIENTS and CARE PARTNERS

Ethical Questions
about Sharing Information



ABOUT THE HASTINGS CENTER'S HELP WITH HARD QUESTIONS SERIES

Life throws you curves.

Beloved parents with Alzheimer's disease who no longer recognize you. Beloved children who can't focus and are failing in school. Infertility. New genetic tests that give you information you don't know what to do with. Advanced cancer and questions about coping with it.

There are facts to gather when confronted with such challenges, and it is important to do so. We have a mantra at The Hastings Center: Good ethics begin with good facts.

But sometimes—often—facts can only take you so far. Facts about the diagnosis of attention deficit hyperactivity disorder do not provide an answer about how to treat your child. Facts about the course of Alzheimer's disease do not help you with the difficult decision of whether to put a parent with the condition who needs constant care in a nursing home. Facts about infertility do not tell you what to do with leftover frozen embryos.

That's because the "facts of life" do not tell you how to live—or how to die. What they provide is information that you must then filter through your personal value system to determine a course of action that makes sense for you and for your family.

This is where bioethics comes in. It can provide moral guidance on common medical dilemmas that individuals face in the beginning of life, at the end of life, and in between. People tend to think that ethics imposes an answer on you—thou shalt not steal. Well, there are some ethical rules, it's true. But ethical solutions often are not absolute. They involve carefully examining your values and balancing competing interests and demands, in particular situations, in light of the most reliable facts.

The Hastings Center's Help with Hard Questions series is designed to help you think through bioethical problems raised by advances in medicine and technology in a way that leads you to solutions that are consistent with your values. These solutions will, of course, be informed by the facts, and also weighted by the experiences of others and the expectations of society at large. Understanding these variables is critical if you are to find ways to live with difficult and sometimes fluid situations that maintain your integrity and dignity, as well as the integrity and dignity of those you love.

The Patient-Care Partner Relationship

Consider the story of the anthropologist, the old lady and the very tough meat. An anthropologist was preparing for his first visit to a remote village. His studies had taught him that the inhabitants of this village subsisted on the meat of a local bird, and that this meat was notably tough and hard to digest. On his first night in the village, the inhabitants invited their visitor to a festive meal. He was presented with a plate of the local specialty. He steeled himself and took a bite. To his surprise, it wasn't as tough as he'd feared. He looked at his hosts, who gestured to an elderly woman at the table, who smiled at the anthropologist. "I chewed it for you," she said.

A woman undergoing treatment for advanced cancer told this story to her friend. "I'm the anthropologist," the woman said. "I have to listen to my doctors tell me how sick I am. It's tough to hear this about your own health, your own life. It can be hard to take in new information during an appointment, especially if I'm feeling lousy that day, or worried about my family, about money, about all the things you worry about when you're sick."

The woman then told her friend: "You're the old lady in the story. You chew things for me. You look up medical information to help me understand what I'm going through, and that helps me figure out what questions to bring up during appointments. If I forget to ask a question, I can rely on you to ask it. You write up the notes so we can keep track of what we know and what we have to stay on top of. And sometimes, it's easier for me to digest bad news when we have a chance to talk it over later.

"These are things I wish I could do for myself. It's hard to accept help. It's hard not to have as much privacy as a healthy person does. But it's also a relief not to have to go through this by myself."

People who are seriously ill often face decisions not only about medical treatment, but how they will *manage* medical treatment. One of the first decisions they face is how and with whom they want to share information about their health and health care.

While some patients choose to manage all details on their own, many patients entrust another person or a small group of people with this information and with the responsibility of providing support during medical treatment.

The person (or team) in this role is sometimes called a “care partner.” The phrase describes a relationship—a partnership—between a patient and another person, one that has been created in response to a health care need. (A patient may or may not use this exact phrase to clarify who plays this role.) The role of care partner is often filled by a patient’s spouse, an adult child, a sibling, a close friend or another loved one. A hospital’s intake staff may ask a new patient if he or she has a care partner.

The following questions are examples of the sorts of ethical issues that can arise around sharing information and supporting values in the patient and care partner relationship:

Why is truth-telling so important when a person is facing medical decisions?

Telling the truth is integral to most people’s understanding of what it means to act ethically in everyday life. In relationships, including health care relationships, truthfulness tends to build trust while lying or evasion tends to undermine trust. Patients also need accurate information to make informed choices about treatment.

A patient and care partner should talk about how the patient prefers to receive information, including what level of medical detail the patient wants and what level of detail the patient wants the care partner to have. For example, in the care partnership described previously, the patient wanted the care partner to seek out further information about the patient’s disease and treatment options. The patient also did not want every conversation with this loved one to be about disease and treatment. Figuring out how she wanted to receive different types of medical information, and sharing these preferences with her care partner as well as with health care professionals, was one of this patient’s first tasks.

New forms of communication, and devices such as smartphones and tablets, make it easier to share health information. Patients may use email, Facebook, or blogs both to share information and to let concerned others know what kinds of material they prefer not to receive. For example, some patients seek out blogs and other first-person accounts written by others facing illness and medical treatment. Other patients prefer not to read this kind of material, or may rely on care partners to vet material that is potentially distressing.

Depending on a patient's diagnosis, a patient may rely on a care partner for a relatively short time (for example, during a course of treatment that is expected to resolve a health problem), or for extended periods of time (for example, during treatment to manage a recurrent condition), or for an open-ended period. Some care partners are also involved in nonmedical aspects of health care, such as helping to resolve insurance problems. A care partner is frequently a patient's advocate inside a fragmented health care system.

Sometimes, a patient's care partner is also the patient's designated surrogate (also known as a health proxy or agent) who is responsible for making medical decisions on behalf of the patient in the event that the patient does not have the capacity to make these

Should a patient ever withhold medical information from a care partner, or vice versa?

A patient has no obligation to share all medical information with a care partner. The patient's full medical history, for example, may include information that is not relevant to the patient's current condition, and that the person prefers to keep private. However, a care partner who lacks basic information about a patient's current condition and treatment will find it difficult to provide support and to be an effective advocate. Establishing some ground rules for sharing information is helpful.

Sometimes, the care partner will receive information at a time when the patient is not present. (For example, a surgeon may speak with a care partner while a patient is recovering from a procedure.) The patient and care partner should talk about how the patient wants situations like this to be handled, and they should share the patient's preferences with health care professionals.

If a patient and a care partner disagree, should the care partner go along with the patient, or challenge the patient?

Like most human relationships, care partnerships may include areas of disagreement and need ways of resolving or managing them. A patient may welcome a care partner's opinion at some times, and at other times may feel that the care partner is being too critical or has failed to understand the patient's perspective. A care partner may worry about being overly critical, and may be uncertain what to do if the patient seems to be making a choice that is at odds with his or her other choices.

Mutual respect, clarity about the patient's values and preferences, and candid discussion about what the patient wants from the care partner—a sounding board? a devil's advocate? a cheerleader? different things at different times?—may prevent some disagreements and help resolve others. Having others to talk with (including professionals as needed) may support both the patient and the care partner and prevent

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decisions. A key difference between these roles is that a patient who is able to make his or her own decisions may want someone to help manage the flow of medical information, the details of medical treatment, and, often, the emotional aspects of being sick and needing care.

As the population ages and advances in medicine allow many patients to live longer with serious illness, the experience of care partnership will be part of the lives of more and more people. This publication describes the ethics of care partnerships—the moral questions and challenges raised by this relationship. These questions are at the heart of what we value as human beings: How should we live our lives? What do we owe one another? What kinds of social

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minor disagreements from escalating.

If a care partner thinks he or she cannot support a patient's preferences, the care partner must talk directly with the patient about this, as it may be necessary for another person to share or take over the care partner's responsibilities.

What if the patient doesn't want to talk with the care partner about something that seems important, like pain?

A care partnership exists because of a person's need for medical care and his or her desire and willingness to work with another person to meet these needs. It is an intimate relationship in which difficult topics are likely to be discussed: the reality of illness, the benefits and burdens of treatment, concerns about dependence, worries about the future, and, in some cases, an uncertain prognosis or the prospect of worsening health. The patient and care partner will also have to figure out the boundaries of the care partnership. For example, a patient may tell a care partner to "stop worrying about me." Does the patient mean that the care partner is being intrusive or controlling? Or is the patient expressing a concern that the care partner is overburdened? The care partner may be unsure, and may also not know how to "stop worrying."

Sometimes a care partner will observe that something seems wrong. For example, the patient appears to be in pain, or describes pain or symptoms that were not expected or are worsening, and yet does not want to talk with anyone about this. Pain is a complicated problem and it can be difficult to talk about. Palliative care—the care of the "whole person," including the treatment of pain and symptoms—offers a way to address this problem no matter what type of medical treatment a patient is receiving. Making sure that palliative care is always available to the patient may prevent suffering. It also gives care partners something concrete to suggest when a patient appears to be in pain.

relationships can help prevent suffering and promote well-being in the lives of others? The questions of the ancient philosophers are the questions that continue to shape ethics in everyday life.

Setting ethical ground rules when a loved one is sick

“Doing the right thing” is a common way to express what it means to act ethically. However, ethical questions involve uncertainty: Am I doing the right thing? Did I do the right thing? Will I do the right thing? Is there more than one right thing? When a person is sick, these questions may present themselves with urgency—sometimes, something must be done now. For example, a treatment that could provide benefits that a patient wants may also carry burdens (such as side effects or monetary costs) that the patient wants to avoid. What’s the right thing to do? Comparing benefits and burdens in terms of a patient’s own values and goals, and the experience of illness and treatment, is something that a patient may

A relationship between a patient and another person that has been created in response to a healthcare need is sometimes called a “care partnership.”

do regularly. The ethical questions that may arise in the relationship between a patient and care partner may be particularly complex, as these two people usually have some other close relationship with one another.

Two areas that may involve ethical issues in serious illness are sharing information and respecting values. Honoring a patient’s right to information about his or her own health and life is central to medical ethics. Health care professionals are also accountable for protecting patients’ personal privacy and the confidentiality of medical information. A great deal of medical information flows from health care professionals to patients: test results, diagnostic information, and so on.

A care partner frequently helps a patient manage this flow of medical information. A patient or care partner may also collect other information about a patient’s condition and treatment options, from Web sites, articles, books, organizations, and peers. According to the Pew Internet & American Life Project, 61 percent of adults in the U.S. were searching for health information online by

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2009, more than half of them doing so on behalf of someone else, and most adults discussed the results of their searches with a loved one. So, some of the ethical “ground rules” of a care partnership are likely to be about information sharing—recognizing that these rules reflect what a patient wants right now, and may need to be updated should the patient’s situation and preferences change. Examples of the sorts of questions about sharing medical information that patients and care partners should work out are:

- What kinds of information will the patient share with the care partner?
- What information does the care partner think he or she will need to know?
- What information does the patient prefer to keep private? If a person who is close to the patient asks the care partner for information about the patient, how should the care partner respond?
- Does the patient want information from sources other than health care professionals?
- What kinds of information or advice does the patient find unhelpful or distressing?

The ways in which a patient and care partner will settle on how information is shared depends on the patient’s personal values, which care partners need to understand, so they can offer knowledgeable support, both in the medical context and in a patient’s day-to-day life. For example, a patient who has children may be concerned about how to continue to be a good parent while undergoing medical treatment. A patient who works, or who volunteers in his or her community, may be uncertain whether he or she can keep up these commitments, and about how much information to share with others. A care partner who is aware of these values may be able to help the patient balance personal commitments and concerns with the demands of treatment.

A care partnership can have core values of its own that can sus-

tain both the patient and the care partner amid the uncertainty and stress of illness and treatment. For example, the value of solidarity may be useful in sustaining a care partnership, because it represents the reciprocal connection between a sick person and a healthier person, and encompasses their shared interests and aspirations. Certain other values, such as honesty and trustworthiness, are crucial both to care partnerships and to relationships between patients and health care professionals.

The test of our values is how well they perform under difficult conditions. In the care partnership described at the start of this booklet, the patient and her care partner used the story of the anthropologist, the old lady, and the very tough meat to check in with each other about how they were managing shared information and how the patient wanted to receive new information while undergoing treatment. The care partner was grateful to the patient for telling this story, as it provided insight into the patient's values and what she trusted the care partner to do. The story—their story—also reinforced their solidarity with each other.

The Hastings Center Guidelines on End of Life Care

The Hastings Center is producing a revised, updated, and expanded version of its historic publication: *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (1987). The new publication, which will be released in 2012, aims to improve the quality of end of life care in the United States by providing ethical guidelines for the current generation of health care professionals on the decisions dying patients, their families, and other caregivers may face. It will also describe the practices, policies, and other systems that support communications and decision making and promote access to palliative care, hospice care, and other services. The project is supported by Sussman Charitable Trust and the Patrick and Catherine Weldon Donaghue Medical Research Foundation.

Practical suggestions for care partnerships

- Recognize the patient and the care partner as individuals whose lives are not limited to the experiences of illness, medical treatment, and caregiving.
- Talk candidly about the patient's values and preferences, including any specific preferences about treatment.
- Patients should introduce their care partners to their health care providers and explain their role. (If the patient has designated a health proxy, this information should also be shared with health care providers.) Clarify whether and to what extent the care partner may, with the patient's consent, communicate directly with health care providers.
- Find out how to consult with palliative care experts to address pain and other symptoms.
- Establish ground rules for sharing information that comes from medical professionals and other sources.
- Recognize that patient preferences and care partner responsibilities may change. Discuss changes as they arise. Address and try to resolve sources of tension.
- Acknowledge emotions related to illness, treatment, and caregiving, as they may be experienced by the patient or the care partner.

RESOURCES

Hastings Center Resources

Carol Levine, “Family Caregiving,” in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book*, The Hastings Center, 2008. www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2172

Bruce Jennings, Gregory E. Kaebnick, and Thomas H. Murray, eds., “Improving Care at the End of Life: Why Has it Been So Difficult?” *Hastings Center Report*, November–December 2005. www.thehastingscenter.org/Publications/SpecialReports/Detail.aspx?id=1344

Carol Levine and Thomas Murray, eds., *The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers*. Johns Hopkins University Press, 2004.

Bruce Jennings, True Ryndes, Carol O’Onofrio, Mary Ann Bailly, “Access to Hospice: Expanding Boundaries, Overcoming Barriers,” *Hastings Center Report*, March–April 2003. www.thehastingscenter.org/Publications/SpecialReports/Detail.aspx?id=1352

Other Resources

Joanne Lynn, Joan Harrold, and Janice Lynch Schuster, *Handbook for Mortals: Guidance for People Facing Serious Illness*, 2nd ed., Oxford University Press, 2011.

Tony Hope, *Medical Ethics: A Very Short Introduction*, Oxford University Press, 2004.

Carol Levine, ed., *Always on Call: When Illness Turns Families into Caregivers*, 2nd ed., United Hospital Fund/Vanderbilt University Press, 2004.

www.getpalliativecare.org – Center to Advance Palliative Care. Includes information about palliative care and how to find it.



The Hastings Center

The Hastings Center is an independent, nonpartisan, and nonprofit bioethics research institute founded in 1969. Its mission is to address fundamental ethical issues in the areas of health, medicine, and the environment as they affect individuals, communities, and societies.

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