

# Sorting out Advance Directives

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By Chris Dimick

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*Important differences exist in advance directives. Only some grant access to another person's medical records, and that can change with time.*

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After 50 years of marriage, Rosa Taylor-Payne noticed even the slightest change in her husband, Marvell Payne. So she started to worry when he would drive past their destination or forget the most direct route.

After his memory loss and confusion increased in 2006, Payne underwent psychological and neurological exams to confirm what his wife had already noticed. His memory was failing, and the cause was Alzheimer's disease.

Concerned for her husband's health and wanting to help, Taylor-Payne was shocked when she was repeatedly denied access to his medical information. Federal privacy laws prohibited the disclosures to Taylor-Payne, even though she was his spouse.

"It made me upset. This is my husband and I've been with him for so many years, but they didn't give a rat about how long I had been with him, they just weren't going to give [the medical information] to me," Taylor-Payne says. "It was just frustrating every time you tried to get information about him, and they won't give it to you because of HIPAA law and all this other stuff. I didn't care-this is my husband."

The Paynes soon learned that if Marvell Payne completed a durable healthcare power of attorney form that designated his wife as his healthcare agent she could take the active role in his care they both wanted. The document would allow Taylor-Payne to sign documents, access and review all of her husband's medical information, and help actively manage his treatment.

After consulting a lawyer and drawing up several advance directive documents, Taylor-Payne had no further problems receiving the records to help her husband with his care.

## At Best, Frustration...

The Paynes' experience is not uncommon. For many people, the first time they hear about the legal requirements for accessing another person's records is when they make their first request. Even determining exactly what legal documents they need can be a challenge.

Important differences exist in advance directives, the legal documents that authorize an individual to manage another person's healthcare. Different directives serve different purposes and convey different rights, including the right to access the patient's medical records.

At best, the confusion results in frustration; at its worst, it can delay or block access to health records that help manage care. For patients and their caregivers, it is important to determine the advance directives they may need well in advance of needing them.

For the HIM professionals in hospitals and other care settings who receive requests for health records, knowing the rights and requirements related to advance directives is essential for ensuring that confidential patient information is disclosed only to authorized persons.

## The Differences in Advance Directives

Advance directives like the durable power of attorney that Marvell Payne completed legally establish who can handle a person's healthcare and finances should the person become incapacitated.

They are the legal documents that a person (the principal) completes that grant another person (the agent) the right to act on the principal's behalf. A person must be capable of understanding and signing an advance directive in order for it to be effective. Depending on the principal's wishes, the directive may take effect before or after he or she becomes incapacitated.

Advance directives are meant to serve as a backup in case a person can no longer handle his or her own healthcare and finances, says Elizabeth Gould, MSW, LCSW, the director of state programs at the Alzheimer's Association.

There are major differences between advance directive documents and the rights they grant both principals and agents, says Leslie Fried, senior attorney at the American Bar Association's Commission on Law and Aging and director of the Alzheimer's Association's Medicare Advocacy Project, based in Washington, DC. Knowing the differences helps a person select and use the right advance directives for his or her situation.

Six advance directives and patient proxy arraignments are common in healthcare. Below is an overview of each, followed by common misperceptions in how they may be used to access another person's protected health information.

### **Power of Attorney for Healthcare and Finances**

Power of attorney documents legally enable an agent to make financial and medical decisions for the principal. Power of attorney for healthcare and power of attorney for finance are typically drawn up in separate documents.

The power of attorney for healthcare allows named agents to represent the principal on all healthcare decisions and grants them access to a person's medical records. These decisions can include choosing a doctor for the principal, authorizing forms of treatment, and selecting care facilities. The agent presents the document to a hospital as proof that he or she has been named as the principal's healthcare agent and can legally make decisions on the principal's behalf.

The power of attorney for finance grants an agent the ability to make decisions about the income and assets of the principal. This includes paying bills and buying or selling property. An agent could present this document at a bank when withdrawing money for the principal.

A power of attorney for healthcare does not grant a person's agent the ability to handle their finances. Similarly, the agent named in a power of attorney for finance cannot make decisions regarding the principal's care and may not access the principal's healthcare records.

Not knowing this distinction can lead to confusion and conflict. Some people incorrectly assume that because they are the agent in one form of power of attorney, they are the agent for all of the person's affairs.

### **Durable Power of Attorney**

The power of attorney designation is not permanent. It becomes invalid if the principal becomes mentally or physically incapacitated.

Only a "durable" power of attorney allows an agent to handle another's affairs in the event of incapacitation-if the principal became mentally incapable as a result of Alzheimer's, for example, or fell into a coma following a car accident.

Many lawyers recommend creating a durable power of attorney for healthcare and finance for this reason, Fried says. State laws vary greatly on all advance directives, but specifically on durable power of attorney. In some states, the durability of power of attorney is implied in the document, while others require the document spell out that the rights are durable.

Durable power of attorney documents can be written to become effective either upon signing or only when the principal's capacity is compromised. For example, a power of attorney for healthcare could go into effect when two doctors judge that a principal is incapable of handling his or own healthcare decisions, Fried says. The document would spell out what incident causes an agent to be granted power.

Until such an incident occurs, principals who create power of attorney documents retain the power to make decisions on their own behalf, and they can override their appointed agent, Gould says—even if their decisions are not what others believe are the best decisions.

## **Executorships and Wills**

A power of attorney agent's legal control over a principal's healthcare and finances ends when the principal dies. At death, control of a person's affairs, including his or her medical records, goes to the person the principal named as the personal representative or executor of their estate. An executor is typically named in a will, another type of advance directive, which dictates who can manage the deceased's estate.

A person named in a will as executor must file documents in probate court in order to receive an official executor document. If no executor was named in a will, an individual would seek court approval to be named the principal's personal representative.

An executor has no legal authority over a principal while the principal is still living. For example, the executor would have no right to the principal's medical records during the principal's lifetime.

## **Living Will**

The living will dictates an individual's preferred medical choices on end-of-life decisions. It can serve as a guide for a healthcare agent who must make healthcare decisions on the principal's behalf.

"It is important to give [agents] guidance, because they are doing substitutive decision making, making a decision in your stead," Fried says. "They need to know what your wishes would be so they can honor them."

It also is important to name someone who can honor your wishes. Fried had a client with ALS who named a close friend as her agent because her husband believed it would be too hard for him to honor her wish to forego life support should she become unable to swallow.

Living wills can stand on their own as a statement dictating what care an individual would like to receive. However, they do not appoint an agent to make healthcare decisions. Because a living will cannot anticipate every medical situation that might occur, they are no substitute for a durable power of attorney agent to fully oversee medical decisions.

Living wills cannot be used to request medical records.

## **Guardianship**

The difference between a power of attorney agent and someone receiving guardianship of a principal is great.

In an advance directive such as a power of attorney, the individual retains control over who handles his or her affairs. Guardianship, on the other hand, is determined by the courts.

"Guardianship is the most restrictive alternative," Fried says. "You want to try everything else before you end up in court."

A guardian, also called a conservator in some states, is appointed by a court to make decisions about another person's care and property if no authorized or capable agent can be identified. Guardianship is granted to a caregiver by a court when it finds that the principal is totally or partially legally incompetent and can no longer handle his or her own affairs. In dementia cases, legal incompetence refers to the person's ability to make rational decisions about his or her care or property.

Guardianship is not necessarily granted over a person's entire life and affairs. A court may assign limited guardianship for specific activities such as healthcare, Gould says.

A hospital could instigate a guardianship proceeding if a patient is incompetent and has no apparent caregiver to make medical decisions or care for them upon discharge, Fried says.

Guardianship expires when the principal dies, meaning the guardian would no longer have access to their ward's medical records. That power would be passed to the executor of the deceased's estate.

In some instances, both a guardian and a power of attorney agent may exist, such as instances where the agent was deemed incapable of fulfilling his or her duties for a short period of time or was only identified at a later date. A full guardianship trumps any power of attorney documents and their named agents.

### **Default Surrogate Statutes**

Some states have passed default substitutive or surrogate decision statutes that establish a hierarchy for naming a healthcare agent if a person becomes incapacitated and has no advance directives. In Maryland, for example, the surrogate is first the guardian (if named), then the spouse, then an adult child of the patient, then a parent of the patient, then an adult sibling, and so on.

In such states, a person who does not want next of kin to be named his or her proxy in the event of incapacitation certainly will want to create advance directives, Gould says.

Not all states have default surrogate statutes, leaving court the only option for establishing an agent in the absence of advance directives.

### **Misconceptions on Rights to Access Records**

Having worked 15 years as a director of a hospital HIM department, Becky Buegel has vast experience fielding requests for patient records. Misunderstandings over the rights a particular document conveys are common, says Buegel, RHIA, CHP, CHC, now the HIM program director at Brookline College based in Phoenix.

For example, someone might present a power of attorney document that pertains to property, not healthcare. Someone else may present a living will. Neither document authorizes access to another person's health records.

Other times a person might hold a power of attorney for healthcare that is invalid because the patient has become incapacitated or has died. Others request records as the guardian of a patient but provide only a petition for guardianship as proof.

Another misconception, Buegel says, is that power of attorney can be transferred. She once faced a situation in which a son was the durable power of attorney agent for his father, and his father was the durable power of attorney agent for his mother. When both the mother and father became incapacitated, the son believed he had become the agent for his mother through his role as his father's agent. This was not the case.

"Power of attorney is a contract between two people," Fried says. It cannot be reassigned.

Differing state laws complicate matters. Take for example a man who executes a durable power of attorney for healthcare in Illinois, his primary residence, but becomes incapacitated in Arizona where he spends his winters. Differing state laws could render the Illinois document invalid in Arizona or require additional provisions in order for it to be honored by an Arizona hospital, Buegel says.

Some advance directives may require supporting documentation. Under Wisconsin law, a durable power of attorney is effective only after two physicians or a physician and a psychologist determine the principal can no longer act on his or her behalf, Buegel says. This medical determination must be stated in a written, signed document and attached to the power of attorney for the power of attorney to be effective.

The most important aspect of the advance directive is ensuring a third party, like a hospital or bank, will accept them. Fried recommends that individuals discuss the advance directive requirements directly with their bank or hospital before drawing up the documents. With the prevalence of financial and healthcare fraud, many hospitals and banks are cautious about accepting loosely documented advance directives.

"There is a lot of concern about fraud, and for good reason," Fried says. "There is no oversight on power of attorney, which is why you have to give it to someone you trust."

**Executor:** The person named in a will to manage the estate of the person with dementia upon his or her death

**Grantor:** The person who creates a living trust is created; for example, the grantor of the John W. Smith Living Trust is John W. Smith; also called a trustor

**Guardian:** The person appointed by the courts to make financial decisions on behalf of the person with dementia; referred to as the conservator in some U.S. states

**Healthcare agent:** The person given legal authority to make healthcare decisions for the principal through a power of attorney for healthcare document; usually a trusted family member or friend

**Legal capacity:** The ability to understand and appreciate the consequences of one's actions and to make rational decisions.

**Principal:** The person with dementia who, through a power of attorney document, legally chooses an individual to make decisions on his or her behalf

**Probate:** The process used by the court to distribute the property of a person who has died

**Summons:** A notice to appear in court; delivered to the person with dementia when a petition of guardianship or conservatorship has been filed on his or her behalf

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## **For HIM Professionals: Due Diligence Required**

HIM professionals have a duty to evaluate each request for a patient's records. They are professionally and legally bound to ensure that confidential information is disclosed only to authorized individuals.

To the patient or caregiver, this scrutiny may look like red tape. But it is in all patients' best interest that their medical information is kept confidential until requestors can prove they have either consent or the legal right to access it, says Buegel.

"This is one of the reasons why most hospitals don't immediately run and fetch a record and copy it for somebody when they first walk in," Buegel says. "We need time to make sure that we have proper authorization and see if there are any issues that exist."

These interactions can lead to frustration and conflict. People typically are seeking another's medical records during a medical crisis. HIM professionals should handle contentious records request delicately and with compassion, Buegel says. But they should not hand over information just to avoid a difficult situation.

"Sometimes people felt like they were jumping through hoops, but it really was in the patient's best interest," Buegel says of her former records request process.

Creating appropriate advance directives helps everyone involved. The correct advance directives protect patients while allowing them to directly dictate who and how others handle their care and finances, says Buegel.

In reviewing an advance directive, HIM staff must ensure the document is valid in their state, effective on that day, and grants powers to access records. They must verify the requestor is the active, named agent or executor of the principal's estate.

"You had to read every document that someone brought in because I think most times the person who brought it in hadn't read it," Buegel says of her past experiences. "They just knew their name is in it, and they signed it."

In states with default surrogate statutes, it may be difficult for HIM staff to verify the legal agent based on the state law alone. In such cases, they should refer to their state law and attempt to contact any known relations higher in the hierarchy (such as a guardian or a spouse) to confirm the legal substitutive agent.

## **Completing Advance Directives in Advance**

Though they are not pleasant to think about, advance directives are important to get in place while a person is healthy and mentally capable. Waiting until a medical emergency arises might be too late.

Once Marvell Payne was diagnosed with Alzheimer's, he and his wife not only created a durable power of attorney for healthcare, but also a durable power of attorney for finances, a living will, and several other advance directives. Advance directives give him and his wife the assurance that their affairs will be in order if his Alzheimer's progresses, Payne says.

"I wanted to do it while I knew what was going on," Payne says. "We are the parents of five children, and if something goes wrong there would be chaos." Establishing his advance directives now eliminates the potential for confusion and conflict, he says.

Fewer than half of severely or terminally ill patients had an advance directive in their medical record, according to research from the Agency for Healthcare Research and Quality. The number of all Americans with advance directives is estimated at just 20 to 30 percent.

Many advance directive documents, like durable power of attorney for healthcare or a living will, are provided free on the Internet and can be completed without legal advice. State bar associations may provide free state-specific advance directive documents. The Web site [Caringinfo.org](http://Caringinfo.org), a program of the National Hospice and Palliative Care Organization, also offers resources and state-specific advance directive documents.

State laws differ on how to make an advance directive legal, which is why reviewing documents with an attorney is a good idea, Fried says.

When creating advance directives, it is always important to name backup agents who can fulfill the duties if the primary agent is incapable or unwilling to do so. Before naming someone as an agent, Fried advises having a conversation with the person about your financial and healthcare wishes. Be certain the person you select is willing and able to serve as an agent.

Finally, let all agents know where you will store the documents, and file your healthcare advance directives with your provider so they are on record in case of an emergency.

During discussions with Alzheimer's support groups, the Paynes have heard many stories of people who never created advance directives and now are too sick to dictate their healthcare and financial wishes or appoint an agent.

"It is so important to do this before it is too late, whether you have an ailment or not," Taylor-Payne says.

"Anything you wait on, you are losing time," Payne adds.

## **Successors and Multiple Agents**

Special circumstances arise when an individual names two or more people as his or her healthcare agents.

This may happen if a parent does not want to choose between two children and names both as agents. However, the situation becomes complicated if multiple people are named to act as agents at the same time.

When this is the case, both agents must sign off on any action in order for it to be valid, says Fried. For example, if a durable power of attorney for healthcare names two concurrent agents, both agents would need to give their consent in order for records to be released to either agent. If there is a disagreement between agents, then nothing gets done. Even if both agents get along, taking action will be hampered if one agent is unavailable for any reason.

Individuals also may name a single active agent and then name a second person as a successor should the first agent be unable to fulfill the duties. This is a recommended practice.

A successor or second named agent only has power of attorney over another when the primary, or first named agent, either denies the power or is incapable of serving. Successor agents must prove that the agent named above them is no longer the legal agent, either through written affidavits or through direct contact with the HIM department, Buegel says.

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