Releasing Information of Deceased Patients

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Developed when modern law concepts were first formed, the mortmain, or “dead hand,” rule prevented the church from exercising undue influence over a soon-to-be-dead penitent to obtain a gift of an individual’s lands in remission of his or her sins. These statutes evolved over time to prevent a person from making distributions of property to charities if he or she did not survive a certain number of years from the making of a will.

Today legislatures still enact statutes that affect the rights of the dead; however, in the HIM arena, many of these statutes grant the dead or their representatives more control over the use and disclosure of the deceased patient’s health information.

The Role of HIPAA

The HIPAA privacy rule requires that a covered entity may not use or disclose protected health information (PHI) except as the rule permits or requires or as the individual who is the subject of the information or the individual’s personal representative authorizes in writing.

A covered entity must obtain the individual’s written authorization for any use or disclosure of PHI that is not for treatment, payment, healthcare operations, or otherwise permitted or required by the privacy rule. Such an authorization must be in plain language and must contain specific information regarding the information to be disclosed or used, the persons disclosing and receiving the information, expiration date, right to revoke in writing, and other data.

The privacy rule also requires a covered entity to “verify the identity of a person requesting [PHI] and the authority of any such person to have access to the [PHI]…, if the identity or any such authority of such person is not known to the covered entity.”[1] It is this last requirement that has primary significance in the management of requests to release records of deceased patients.

One of the fundamental principles of the HIPAA privacy rule is that deceased patients continue to have specific expectations of privacy following death. Commentary to the privacy rule makes clear that one of its purposes is to afford deceased patients the same rights of control over their protected health information as live patients. These rights of control are to be exercised only through the deceased patient’s personal representative, which is defined as a person with legal authority to act for the estate.

This requirement for legal status requires covered entities to verify a personal representative’s authority to act on behalf of a patient, but the privacy rule defers to state law to establish who is a personal representative (subject to some restrictions involving patient safety).

Personal Representatives and Authorizations

There are several ways in which a person can receive personal representative status. Each state has a formal process by which the executor or administrator of an estate can be identified. Additionally some states also empower the holders of advance directives or durable powers of attorney for healthcare to obtain records on deceased patients. Providers should insist on official documentation from the appropriate court or through receipt of a signed copy of the advance directive or power of attorney evidencing this status.

However, a patient can authorize release of information while alive that can be fulfilled after he or she has died. For example, a HIPAA-compliant authorization can have perpetual effect. An authorization signed as part of a life insurance policy application can permit a covered entity to release records relating to the death of the insured patient so that a claim can be paid, years after the insurance was applied for and issued. In fact nothing in the privacy rule requires a covered entity to treat a validly executed authorization as expiring upon a patient's death, unless its terms so require.

This burden is slightly different for parents of deceased minor patients. Minors cannot sign advance directives, so there is no formal documentation (other than a birth certificate) that shows who a minor's parents are. Presumably the treating provider obtained some proof of the parent's status at the time the minor patient was treated (through the execution of a consent to treatment), and this proof will make it easier to verify the parent's right to obtain or authorize release of the minor patient's records.

If no such proof was obtained, or if a person other than a parent consented to treatment (e.g., a grandparent or other person standing *in loco parentis*), providers should ask for and obtain a copy of the patient's birth certificate before releasing records of deceased minors.

The drafters of the privacy rule were mindful of the need that family members might have to access the records of their deceased relatives for their own treatment purposes. For example, genetic information might be helpful in determining whether a patient might develop any number of genetically linked diseases. The commentary to the privacy rule suggests two separate pathways to obtain this data: qualify as a personal representative or request access for purposes of your own treatment (to the extent that more stringent state laws would not prevent that access).[2]

State Law Wrinkles

Notwithstanding the broad reach of the privacy rule, many states have established legal systems that permit the surviving spouse or other descendants to gain access to the records of deceased patients, even if these individuals are not the formally appointed personal representative of the patient's estate.

Such status does not usually have any accompanying official documentation, and providers do not routinely request copies of birth or marriage certificates to prove that a person is the surviving spouse or child of a deceased patient. These releases are usually required by law and thus are pre-empted by HIPAA's ordinarily more protective regime.

However, this does not modify the covered entity's duty to verify the identity and status of the person requesting the records. Some states require a sworn statement of authority in order to obtain records under these statutes. In states where this access is permitted and there is no corresponding statutory obligation to provide a sworn statement of authority, covered entities should consider requiring one in order to help meet their verification burden.

There are also statutes that allow family members to restrict access to otherwise public documents such as coroner's findings and photographs taken in autopsies. Perhaps the most highly publicized example of such legislation is the Earnhardt Family Protection Act passed by the Florida Legislature to protect the autopsy photos of NASCAR racer Dale Earnhardt from disclosure to the press. Providers who participate in autopsies or post-mortem examinations need to be aware of these statutes in their jurisdictions and be prepared to withhold such records from further disclosure if required.

Finally, in situations in which family members seek information on a deceased patient for their own treatment purposes, more stringent state laws must be taken into account. In states where there is no continuity of care exception to laws requiring patient consent to release medical information, family members will have to qualify as personal representatives in the absence of an authorization signed by the patient while alive. Families with a history of genetically linked diseases might be well advised to consider some type of post-mortem information sharing to make diagnosing and treating these diseases easier.

The biggest challenge in constructing a legally compliant release of information policy for deceased patients is to decide how and with what documentation a provider is going to verify the identity of persons (other than the patient) that request access to or authorize the release of the deceased patient's records. Providers usually shy away from erecting roadblocks to family members of the deceased; however, HIPAA and other state privacy laws generally do not have exceptions for these releases.

At the same time, provider policies should acknowledge that deceased patients may act after their death through the execution of valid authorizations and other directives. Remembering that the dead have an expectation of privacy and some control over their medical records should assist organizations in implementing and enforcing a sensible policy.

Notes

1. HIPAA. 45 CFR § 164.514(h)(1)(i).
2. The privacy rule defines “treatment” as broader than the treatment of the patient whose protected health information is requested, and specifically includes the treatment of others.

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