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Law and Practice

Advocacy in a Post-HIPAA World

By Hilary Sohmer Dalin

Elder law practitioners or other advocates frequently need access to medical records or information from clients' medical providers, insurance carriers, contractors, or managed care organizations. However, advocates may have found that long-established practices for securing documents or discussing cases with these and other entities, called "covered entities" by the HIPAA privacy regulation, are no longer honored under HIPAA. Advocates now must determine whether or not they have the legal status to require the entity in question to disclose protected health information.

What Is the HIPAA Privacy Rule?
See page 4

The HIPAA-Compliant Authorization

Advocates generally need a HIPAA-compliant authorization to seek disclosure of medical records from health care providers and other covered entities. The regulations set forth the requirements for a HIPAA-compliant authorization.[1] The authorization must:

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- Be separate from any other authorization or retainer agreement or financial grant of a power of attorney.[2]
- Be in writing and in plain language (not "legalese").
- Identify specifically what information the patient wants to access.
- List the name and organization to which the patient wishes the information disclosed.[3]
- Identify the covered entity from which disclosure of protected health information is authorized.
- State the purpose of the disclosure. It is sufficient for a patient to write "at my request."[4]
- Include an expiration date or event such as "one year from the date I signed this authorization," or "until my appeal is concluded."[5]
- Contain the dated signature of the patient.

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To be HIPAA-compliant, the authorization must also include mandated notices to the patient.[6] The required notification statements are:

- The patient's right to revoke the authorization. If a patient retroactively revokes an authorization, the revocation will not apply to disclosures made by a covered entity before it became aware of the revocation.
- A warning that disclosures to non-HIPAA-covered entities may be disclosed to others who are not subject to the HIPAA privacy rule.

The preamble to the Final Rule modifications suggests that it is permissible to add to the mandated statement information about any legal or contractual obligation between the patient and a non-HIPAA-covered entity, such as the lawyer's ethical obligation to maintain client confidentiality.[7]

Are Advocates Also Personal Representatives?

Can the lawyer or other advocate claim status as a personal representative and accordingly obtain protected health information without first obtaining a HIPAA-compliant authorization?

The privacy rule defines a personal representative as one who is authorized under other federal, state, or local law "to act on behalf of an individual who is an adult or emancipated minor in making decisions related to health care…."[8] Examples include a parent of a minor child or guardian of an incapacitated adult. The rule applies also to records of a deceased individual, with the executor of an estate considered a personal representative. The preamble to the Final Rule states: [w]e intend this provision to apply to persons empowered under state or other law to make health-related decisions for an individual, whether or not the instrument or law granting such authority addresses health information."[9] The preamble does not indicate whether authority to act on behalf of an individual in decisions related exclusively to health care payment confers personal representative status sufficient to access personal health information.[10]

This regulatory definition of personal representative does not mesh with the services provided by lawyers and other advocates, who do not and should not have health care decisionmaking authority for their clients, but who do need access to medical records in order to provide competent representation. A narrow interpretation of the definition may make disclosure to advocates who assist health care consumers with obtaining coverage by Medicare, Medicaid, or other public and private health care insurers harder. It may also place consumers and their advocates in a difficult position—the consumer may feel compelled to relinquish more

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authority over health care than she wishes in order to grant her advocate personal representative status, while the advocate could find herself with the authority to make health care decisions on behalf of a client when all she needs is to review files for a coverage claim. Advocates may need to pursue other avenues for obtaining this information, as discussed below.

Disclosure to Others

As noted above, the HIPAA privacy rule allows covered entities to "disclose to any other person identified by the individual, protected health information directly relevant to such person's involvement with the individual's care or payment related to the individual's health care."[11] The regulation also provides other opportunities for disclosure of protected health information to those involved with the individual's health care. A covered entity may disclose the location, general condition, or death of an individual to anyone who is "responsible for the care of the individual."[12] When the patient is not present, or lacks the capacity to consent or object to such disclosures, "… the covered entity may, in the exercise of professional judgment, determine whether the disclosure is in the best interests of the individual and, if so, disclose only the protected health information that is directly relevant to the person's involvement with the individual's health care."[13]

State Health Insurance Assistance Program (SHIP) Network

The federal Centers for Medicare and Medicaid Services (CMS) has devised an alternative system to permit telephone disclosure of protected health information to selected paid and volunteer staff of the State Health Insurance Assistance Program (SHIP) network. Called the "Customer Service Representative (CSR) procedure," the process enables SHIPs to get claims information from Medicare fiscal intermediaries or carriers.

SHIPs are directed to submit written HIPAA-compliant authorizations whenever possible. In the alternative, they are urged to arrange for a three-way telephone conversation during which the CSR can ask the client to divulge confidential information (such as a Social Security number) to confirm identity. The client is asked by the CSR to articulate an authorization to disclose protected health information to the SHIP staff. Only when the SHIP is not able to arrange for the contractor's CSR to see a written authorization or hear an expression of consent from the SHIP client on the telephone does the CSR procedure come into play. The procedure features a special unique identifier number that has been issued to key SHIP personnel, both staff and volunteer, in each state. The SHIP staff presents the unique identifier number to the carrier or fiscal intermediary CSR and the CSR discloses the requested protected health information.

The SHIP CSR procedure is premised upon the regulation providing that covered entities may "disclose to any other person identified by the individual, protected health information directly relevant to such person's involvement with the individual's care or payment related to the individual's health care."[14]

Adult Protective Services

Privacy questions for Adult Protective Services (APS) programs involve reporting requirements and confidentiality of records. Does HIPAA permit covered entities, *e.g.*, health care providers, to report suspected elder abuse or neglect to APS without patient authorization? What responsibility does APS have to maintain confidentiality of that information, or to allow the individual access to it?

APS is not a covered entity and, even if it was, HIPAA would not affect state elder abuse reporting requirements. HIPAA allows covered entities to disclose protected health information without authorization when required by state law. This includes when related to public health and when reporting abuse or neglect when the disclosure is made to a government authority, including a social service or protective services agency authorized by law to receive such reports.[15] A covered entity making such a report must inform the individual in question or the personal representative that such a report has been made, unless the entity reasonably believes that informing the individual would place the individual at risk of serious harm, or that the personal representative is responsible for the injuries in question.[16]

Long-term Care Ombudsman Program

The U.S. Administration on Aging has determined that Long-term Care Ombudsman Programs are health oversight agencies because they have oversight responsibilities regarding the health care system. As such, the ombudsman has access to resident clinical records. Nursing homes may share other resident protected health information with the ombudsman, even in the absence of a HIPAA-compliant authorization.[17]

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The May Versus Must Dilemma

While disclosure to personal representatives is mandated, disclosure to others, even to those who hold HIPAA-compliant authorizations, is generally discretionary. The regulation expressly allows covered entities to share relevant medical information with family and friends or others involved in the patient's care if the covered entity could reasonably infer, based on professional judgment, that the patient does not object. For example, a doctor may give information about a patient's mobility limitations to a friend driving the patient home from the hospital, may discuss payment options with the patient's adult daughter, or may instruct family members about medication dosages. In an emergency, a doctor may share medical information about the patient's condition with a spouse or other family member. The standard for such disclosures is professional judgment and best interests of the patient.[18]

Some covered entities have reportedly declined to disclose protected health information to advocates. For example, a blind and ill consumer who was not physically able to receive her own medical records was not able to persuade the health care provider to disclose the records to the advocate working on her behalf to obtain the Medicare-covered services that she needed.

If a covered entity refuses access to a client's personal health information, the following strategies may be effective:

- If you have a HIPAA-compliant disclosure, give the covered entity a copy plus, if necessary, a reminder that HIPAA allows disclosure pursuant to a valid authorization.
- Ask your client to request disclosure and then turn the records over to you.
- Ask your client to request disclosure and direct the covered entity to send the information to you.[19]
- Arrange for your client to make the request for disclosure in person and in your presence.[20]
- If your client is unable to request disclosure, ask the client's family member to request disclosure of such protected health information as is necessary and relevant to the family member's involvement in the care of the patient, and then send the information to you.[21]
- Arrange for disclosure to another covered entity with which the patient has a relationship. Ask the second covered entity to make disclosure to an advocate who has been given a HIPAA-compliant authorization and/or to help the patient obtain access or coverage of a disputed treatment option.

Note: While covered entities may charge reasonable fees for photocopying records, they are not permitted to charge for searching or retrieving medical records.

Obtaining Protected Health Information for An Administrative Appeal

As noted in the sidebar "What is the HIPAA Privacy Rule?" on page 4, there are some exceptions to the obligation of covered entities to disclose protected health information to a patient.

The exception for records compiled in reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding is particularly problematic for advocates. Individuals frequently need their medical records in order to pursue an administrative appeal when Medicaid or Medicare denies eligibility, access to a facility, or payment for care. The need for medical records is especially critical in the context of managed care decisions in Medicaid or Medicare, or when an individual must pursue external reviews of a private managed care plan decision. Medical records are also essential for clients wishing to appeal administrative decisions about their entitlement to disability benefits.

While covered entities are not compelled to disclose protected health information compiled in anticipation of a legal proceeding, nor are they prohibited from disclosing that information. The preamble to the Final Rule supports this position.[22]

> "... [W]e permit covered entities to disclose protected health information in a judicial or administrative proceeding if the request for such information is made through or pursuant to an order from a court or administrative tribunal or in response to a subpoena or discovery request."[23]

Moreover, the preamble explains that absent a judicial or administrative subpoena, covered entities may disclose medical records only after obtaining "... either (1) satisfactory assurances that reasonable efforts have been made to give the individual whose information has been requested notice of the request, or (2) satisfactory assurances that the party seeking such information has made reasonable efforts to secure a protective order that will guard the confidentiality of the information."[24] In the context of administrative hearings, usually the client is the one whose information is sought to be

disclosed, so that person's consent should resolve most problems. Fortunately, we are not yet aware of any instance in which this provision has been used to deny advocates access to medical records needed to pursue an administrative appeal regarding a health care consumer's entitlement to health care or coverage. However, if the issue should arise, advocates could use the language of the preamble to argue that the drafters were not considering the typical public benefit eligibility or coverage appeal, but rather were concerned about adversarial proceedings in which a patient's records could be used against her interests.

Other laws give individuals access to certain medical records in the context of administrative appeals, and the privacy regulations can create confusion among covered entities as to their responsibilities regarding disclosure of medical records to those appealing administrative decisions about their own health care access or coverage. Advocates may argue that the HIPAA rule should not be construed to preempt laws that give health care consumers greater rights of access to their own medical records for the essential purpose of obtaining needed health care or coverage.[25]

When Does HIPAA Preempt State Law?

State laws that are more protective of the privacy of protected health information (*e.g.*, HIV or AIDS information) or that make it easier for patients to gain access to their own protected health information generally are still applicable. For example, the privacy rule allows covered entities to charge patients reasonable fees for photocopying medical records, but many states limit the charges that may be imposed for copies of medical records, or direct that certain records are available to certain categories of patients without charge or at minimal cost. HIPAA would not preempt those state rules.

Engaging Covered Entities in Discussions About Clients' Cases

It is not always practical for an advocate to obtain a signed authorization for disclosure of protected health information from a client. Where time is of the essence, such as when a client has an urgent or emergency need for care, it may be impossible to obtain a written authorization for disclosure to the advocate for access to the care. In other situations, such as significant geographic distance between the client and the covered entity, an advocate will have no choice but to try to discuss protected health information with the covered entity by phone. The advocate may need to leave a message for covered entity personnel, or the client might not be available at the time when the covered entity staff is available to discuss a matter. Some vulnerable clients have no access to a telephone, or rely upon public telephones. Few clients have ready access to fax machines. Mailing an authorization and waiting for the client to sign and return it by mail can cause substantial delays to needed advocacy.

Strategies that might help in such situations include:

- Fax the client's signed authorization to the covered entity. While some covered entities have questioned the validity of faxed authorizations, the U.S. Department of Health and Human Services' Office of Civil Rights (OCR) appears to allow this practice. Their Web site includes a question about whether covered entities may fax protected health information among themselves. The answer is in the affirmative, with the caveat that the covered entities should take all reasonable steps to safeguard the privacy of the faxed information.[26] The same considerations would apply when individuals fax an authorization to disclose protected health information to a covered entity.
- Hold a three-way phone conversation for the patient, the advocate, and the covered entity. This might open communications and allow advocacy to proceed. During the phone call, the patient can notify the covered entity of her consent to the disclosure.
- Discuss coverage criteria with covered entity and request information pertaining generally thereto. This could be a satisfactory alternative to asking for disclosure of protected health information.
- Provide the information necessary to advocate on the client's behalf to the covered entity without requesting disclosure of protected health information.

Practical Considerations for Advocates

Medical Authorizations

Attorneys and other advocates who expect to need access to protected health information should make sure their authorizations to release medical records that they give to their clients contain HIPAA-compliant language. The HIPAA-compliant authorization can be on firm or program letterhead or plain paper; it need not be on the covered entity's letterhead or form.

Advance Directives

An attorney-in-fact under a financial power of attorney is not considered a personal representative for HIPAA purposes, and would not have the right to disclosure of private health information. However, if the attorney in fact is responsible

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for paying for the patient's health care, he or she would have access to the health information necessary to undertake that task.

An individual authorized to make health care decisions on behalf of an incapacitated person under a health care power of attorney or state health care consent law would be considered a personal representative. A health care surrogate whose authority is limited to emergency or end-of-life decisions may not have the right to access information that is unrelated to emergency or end-of-life decisions.[27]

Some attorneys who draft advance directives are, to be unequivocal and thorough, including language in the document that expressly mentions HIPAA and identifies the health care agent as the personal representative. This is not technically necessary since a health care agent under state law is a personal representative for HIPAA disclosure purposes, but it may serve to facilitate communications between the agent and the health care provider.

One issue still to be clarified concerns the use of springing powers of attorney (POA)—both for property and for health decisions. The proposed agent does not have the status of personal representative until the power has sprung, but how does the proposed agent get medical information about the principal's capacity in order to make the power effective? It is possible to draft a separate patient advocate designation form that, in effect, creates a limited power of attorney as to the release of medical records, rather than authorizing all health care decisions. Another option would be to include a release provision in the POA that is immediately effective, although the remaining powers must still be triggered in order to spring.[28] Some elder law attorneys have suggested avoiding the use of springing powers of attorney unless state law requires them.

Guardianship

Guardians of the person of an incapacitated adult, including public guardians, qualify as personal representatives under HIPAA because they are designated by state law to make health decisions for the ward. No additional language is needed in the court order appointing the guardian of the person, but as with the health care power of attorney, including in that document HIPAA-compliant language authorizing the guardian to access private health information from covered entities might forestall misunderstandings with health care providers.

Guardians or conservators of the property are not personal representatives because they do not make treatment decisions. They would, however, have access to private health information to the extent necessary to pay for care, but likely would need specific authorization to obtain additional information.

HIPAA privacy issues may arise in those states where petitions for guardianship must be accompanied by medical certificates or affidavits in support of the allegations in the petition. If the petitioner is not a covered entity with whom the doctor could share patient identifiable information, the doctor may be reluctant to complete a certificate without the authorization of the patient or patient's personal representative. It might be possible for the practitioner to argue that the certificate or affidavit is a requirement of state law, and therefore a permitted disclosure. If the requirement is in court rules, but not state guardianship law, one solution might be to amend state guardianship laws to require covered entities to provide the necessary information without consent or authorization, thereby fitting within the "required by law" exception. Meanwhile, a petitioner might need to ask the court to order the release of the necessary information. These issues will require further exploration.

Conclusion

The HIPAA privacy rule has presented many problems, as well as questions, for elder law attorneys and other advocates and their elderly clients. A close reading of the regulations in the context of the important dual purposes of the privacy rule, will help advocates to seek and identify solutions to the many barriers to accessing information that advocates have encountered since the HIPAA privacy rule was implemented. The Health Assistance Partnership and the National Health Law Project have suggested to OCR modifications to the HIPAA privacy regulations to redress the some of the critical issues for advocates as discussed in this article.[29]

Notes

1. 45 C.F.R. §164.508(c). An authorization to disclose psychotherapy notes must be separate from a general authorization to disclose protected health information. 45 C.F.R. §164.508(b)(3)(ii).
2. 45 C.F.R. §164.508(b)(3). A health care proxy appointment may, indeed *should*, grant the surrogate decision-maker authority to receive disclosure of protected health information. It is advisable to include language making it clear that the substitute decision-maker is to be treated as a personal representative. *See* Office of Civil Rights, U.S. Department of Health and Human Services-HIPAA, "Can I access someone's medical record if I have that person's health care proxy?" at www.answers.hhs.gov/.
3. The regulations permit an authorization to designate a class of parties from or to whom disclosure is authorized, such as "from my

physicians" or "to any advocate employed or volunteering for the XYZ consumer assistance program." 45 C.F.R. §164.508(c)(iii).

4. 45 C.F.R. §164.508(c)(iv).
5. Advocates have reported that some covered entities are unreasonably dictating restrictive expiration dates, such as requiring a new authorization every two months. The regulation does not contemplate such a practice. It requires that the authorization contain an expiration date or event that relates to the individual or the purpose of the use or disclosure." 45 C.F.R. §508(c)(v).
6. 45 C.F.R. §164.508(c)(2).
7. *See,* 67 Fed.Reg. 53182, 53222 (Aug. 14, 2002), http://www.access.gpo.gov/su_docs/fedreg/a020814c.html.
8. 45 C.F.R. §164.502(g)(2). *See also* 45 C.F.R. §502(g)(3) for treatment of parents and guardians of unemancipated minors.
9. 65 Fed. Reg. 82500 (Dec. 28, 2000).
10. *See* 45 C.F.R. §164.502(g), stating that a personal representative is a person who has authority under other law "to act…in making health care decisions," on behalf of an adult or an unemancipated minor or a deceased individual. This section should be read in conjunction with 45 C.F.R. §160.103, which defines health care for purposes of the HIPAA privacy rule as "care, services, or supplies related the health of the individual." Accordingly, a grant of authority to make health decisions confers personal representative status under HIPAA. Conversely, a person who is granted limited authority to make particular decisions is not likely to have access to PHI.
11. 45 C.F.R. §164.508(b)(i).
12. *Id*. §164.508(b)(ii).
13. *Id*. §164.508(b)(3).
14. *Id*. §164.508 (b)(i).
15. *Id*. §164.512 (b) and (c).
16. *Id*. §164.512 (c)(A).
17. U.S. Dept. of Health and Human Services, Administration on Aging, Information Memorandum AOA-IM-03-01, Feb. 4, 2003, http://www.aoa.gov.
18. 54 C.F.R. §164.510(b).
19. Note: this is an informal suggestion offered to HAP by the HHS Office of Civil Rights.
20. 45 C.F.R. §164.510(b)(92).
21. *Id*. §164.508(b)(1)(i).
22. 65 Fed. Reg. 82462, 82529-82531 (Dec. 28, 2000).
23. *Id*. at 82529.
24. *Ibid*. at 82530.
25. *See* 45 C.F.R. §160.202.
26. *See* Office of Civil Rights, U.S. Dept. of Health and Human Services-HIPAA, "Can a physician's office FAX patient medical information to another physician's office?" at www.answers.hhs.gov/.
27. *See* Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg., 82464, 82634 (Dec. 28, 2000).
28. Thomas J. Murphy, *Drafting Health Care Powers of Attorney to Comply with the New HIPAA Regulations*, 15 *NAELA NEWS* 4, Aug. 2003.
29. For information about HAP, and NHeLP's request for modifications dated August 7, 2003, please contact Cheryl Fish-Parcham, Medicaid Coordinator, Health Assistance Partnership at cparcham@healthassistancepartnership.org or Steve Hitov, Managing Attorney, National Health Law Project, at hitov@healthlaw.org.