



PRIVACY AND CONSENT FOR CAREGIVERS

What **Family Caregivers** Need to Know

Being a caregiver isn't easy to begin with, and the challenges that can keep you from being a true care partner can make things even harder. Here are some of the privacy and consent challenges you may face as a caregiver:

- You may need to make repeated efforts to get copies of health records from a variety of providers who are providing care to the person you're trying to support.
- You may be refused access to copies of test results or other health records.
- Providers may be reluctant to hear your important insights and updates about the patient's health.

And to complicate things even further:

- There is no consistent way across all parts of the health care system for the patient you are trying to support (or their substitute decision-maker) to provide a blanket consent for access to their health information.
- This consent typically needs to be repeated with each provider, and sometimes needs to be re-introduced at subsequent appointments.

So what do you, as a caregiver, need to know, to help you navigate these privacy and consent issues?

- Your access to the patient's personal health information requires the patient's consent. With the patient's consent, you have access to their personal health information and actual health records, or it may also give you the ability to participate in discussions with the provider about the patient's care, giving and receiving information.
- It is reasonable for you to ask the patient you are caring for to consent to the provider sharing personal health information with you.
- Ask for a *Release of Information* form for the patient to sign, or ask the provider to document the patient's consent in the health record and make sure that the provider's staff is aware of the documented consent.
- It's okay for you to remind providers that they are permitted to share certain information with you based on the consent the patient has given.
- If a provider refuses to give the patient the right to access his or her own health record, or refuses to disclose it to you with the patient's consent, the provider may also need to be reminded that personal health information belongs to the patient, and that health privacy rules give rights of access and release with consent.

ABOUT THIS DOCUMENT:

This document summarizes some of the information found in The Change Foundation's report, *Making Privacy and Consent Rules Work For Family Caregivers*, which sets out to explain how the *Personal Health Information Protection Act, 2004* (PHIPA) and the *Health Care Consent Act, 1996* (HCCA) apply to caregivers. To read the full report, please visit ChangeFoundation.com.



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