



# Caregivers

Open notes can be a tremendous resource for those who help manage the care of others nearby or from a distance. You'll find evidence here for doctors, nurses and other health care professionals.

- The growing need for caregivers
- Considerations for sharing notes with caregivers?
- How do caregivers benefit from accessing notes?

## The growing need for caregivers

Family and friends often play a pivotal role as caregivers or care partners, managing the health needs of those who are more vulnerable, including organizing medical appointments and tasks and communicating with health care professionals. The need for clinicians to engage more effectively with these individuals has been well documented by the AARP, the New York Times and the recent National Academies of Sciences, Engineering and Medicine (NASEM) report, Families Caring for an Aging American. Fully transparent, online patient portals that include your notes can help both patients and their care partners enormously in accessing health information and participating more actively in care.

Among the initial group of patients in 2010 to read their medical notes using online patient portals, up to 40% reported sharing their notes with someone outside of the formal health care system. Recent research has examined which patients choose to share notes, and why they do so.

### Study highlights:

- Patients of all ages share access to their patient portal account.
- 42% say they share access because their care partner helps them manage health care activities.
- 30% say they share access with a care partner in case of emergency.
- 18% say they share access because they themselves do not use a computer.

↪ Care Partners and Online Patient Portals, JAMA (<http://jamanetwork.com/journals/jama/fullarticle/1810285>)

↪ Family Caregivers and Consumer Health Information Technology, JGIM (<https://www.ncbi.nlm.nih.gov/pubmed/26311198>)

↪ Patients, care partners, and shared access to the patient portal: online practices at an integrated health system, JAMIA (<https://academic.oup.com/jamia/article/23/6/1150/2399296/Patients-care-partners-and-shared-access-to-the>)

↪ Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead, Annals of Internal Medicine (<http://annals.org/aim/article/1363511/inviting-patients-read-doctors-notes-quasi-experimental-study-look-ahead>)



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## Considerations for sharing notes with caregivers

**Share online or on paper.** While online access lets care partners obtain information easily, when they need it, printing and mailing notes can be highly effective for those without computer access.

**Offer formal proxy access.** A growing number of health systems invite patients to grant care partners secure proxy access, enabling them to read notes, access test results, communicate electronically with clinicians, schedule appointments, or request prescription refill .

“As consumer health information technology becomes more mainstream, the ability of clinicians to differentiate the identity of who—the patient or an involved family member or friend—is exchanging secure email messages, refilling medications, and viewing patient health information will become increasingly important in the delivery of safe and clinically appropriate care.”

—JENNIFER WOLFF, PHD, JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH

**Respect privacy.** Ideally, patients could set preferences for what they want to share with their care partner. Such granular control over privacy is now technically feasible, yet rarely available. In the future, for example, a patient might authorize a paid attendant or informal care partner to schedule appointments or refill prescribed medications, while electing to withhold access to other personal health information.

**Spread the practice.** Making both patients and families aware of the benefits of reading notes may require outreach and marketing efforts by health systems and health professionals.

## How do caregivers benefit from access to notes?

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule provides patients the right to access their own medical records and permits sharing this health information with involved family members, friends, or professional caregivers. Open notes make that process easier and more efficient .

Research indicates that such practice was overwhelmingly endorsed as beneficial by patients and those who care for them. Moreover, the benefits of open notes may be as powerful for care partners as for patients themselves, offering an invaluable tool for improving transparency, communication, and continuity of care. By generating more productive discussions and greater agreement about care plans, open notes can create a stronger patient-care partner therapeutic alliance.

### Study highlights:

- 88% of patients and 86% of care partners said they had better formulated questions for the doctor.
- 86% of patients and 82% of care partners said they had more productive discussions about the patient's care.
- 85% of patients and 79% of care partners stated they were more likely to agree about the patient's treatment plan.
- 94% of patients and their care partners said they had a better understanding of patient health conditions, better remembered the patient's care plan, and felt more in control of care.
- 71% of both patient and care partners reported patients taking medications as prescribed more often.
- 33% of care partners accessed notes because they were not able to attend an appointment.
- Only 1 in 10 patients voiced concerns about privacy.



**Giving care partners what they need.** Family members and care partners are among the most vigilant of health system stakeholders. Providing them timely access to accurate and comprehensive information can enable families to support patients proactively in managing health and coordinating care.

*“My husband is very hard of hearing, and so you can imagine, even with perfect hearing I miss what doctors say sometimes, and he’s really lost. It’s been a godsend that I can find out what the doctor told him because he doesn’t get it right or he only heard part.”*

—MARY IS ABLE TO READ HER HUSBAND’S MEDICAL NOTES

**Navigating the health system.** Managing health care demands can be difficult, particularly for individuals with complex health needs who often see multiple health care professionals. Providing access to notes can help ensure that everyone on the care team, including the care partner, is on the same page with the goals of care. Sharing notes may also benefit you by streamlining the flow of information among your care team, your patient, and his/her care partner.

*“I know what the doctor’s plan is for my mom even when I am in Boston and she is in South Carolina. I can look it up and say okay they are changing her medicine, her blood pressure medication. I don’t have to call them. He does not have to call me back which saves a lot a time for him because we are all on the same page and I can oversee it and know that she is getting what she needs.”*

—JENNIFER, A DAUGHTER

**Bridging the gap for those with limited English/health literacy.** Although access to information through patient portals brings many benefits, not every patient has a computer and not everyone with a computer knows how to access and use the information in the health record. In addition to helping care partners manage health activities, Wolff’s study suggests that shared access is an underused strategy that may help patients bridge health literacy deficits and lack of experience with technologies.

*“In some situations, she comes alone to the appointments and I would like to know what the doctor said in case she couldn’t understand very well and the OpenNote is there for me, to teach me, for me to learn what was the communication between my sister and the doctor, what they say, what they recommend and how can I help her in order to become safe and healthy. So, I think the OpenNotes, is a wonderful tool for me and my family members.”*

—MERELYN, A SISTER

