

Resource Document on Interacting with Caregivers

Council on Geriatric Psychiatry

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Introduction

In this document, we address ethical and legal issues related to involving caregivers in the treatment of patients and provide a comprehensive approach to the engagement of caregivers in the treatment process. This approach revolves around the development and implementation of a caregiver plan (CGP). **It is important to note that the development of a formal CGP does not reflect current practice in the field.** The discussion of a CGP in this document is for education: to describe a potential best practice. Given the complexity of managing caregivers' involvement, practitioners may find it useful to create formal CGPs.

Family members and other caregivers play a vital role in the care of their loved ones. A recent position paper of the American College of Physicians (ACP) summarized the importance of relatives, partners, friends and neighbors in medical care:

Family caregivers play a major role in maximizing the health and quality of life of more than 30 million individuals with acute and chronic illness. Patients depend on family caregivers for assistance with daily activities, managing complex care, navigating the health care system, and communicating with health care professionals (1).

In no other field of medicine is the importance of caregivers greater than in psychiatry. And in no other field is the management of professionals' interactions with patients and caregivers as complex:

- The need for caregiver involvement in psychiatric care is a consequence of the nature of mental disorders and their associated functional impairments. Psychiatrists treat patients with a range of disorders that may affect cognition, including psychotic, mood, substance use and addiction, neurocognitive (e.g., dementias and traumatic brain injuries), and neurodevelopmental disorders. These mental disorders often impair cognitive abilities and, as a result, patients may have impaired ability to understand treatment options, to make treatment decisions, to recognize worsening symptoms or problems in life, and to direct the flow of information related to their care.

Disclaimer

The purpose of this document is to provide education regarding interacting with caregivers. It is not intended as a clinical guideline or as a statement of the standard of care.

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- Some patients have a need for significant and ongoing support from caregivers. A substantial proportion of those with serious mental disorders will face lifelong disability, will have an inability to compete for employment, and will rely on entitlement programs for subsistence. On their own, some may not find even this minimal level of support. Caregivers play an important role by providing financial assistance, housing, and other material support necessary not only to facilitate care for their loved ones, but also to provide for food and housing. Caregivers also play an important role in providing emotional support to patients.
- Caregivers are particularly important in psychiatric care because the onset of the disabling effects of mental illness may occur early in life. In such cases, a large proportion of the lifespan is affected and the need for assistance is great. For those with early onset of illness, such as schizophrenia, caregiver involvement may span several decades.
- Managing psychiatrist-patient-caregiver relationships is complicated by the episodic nature of most mental disorders. During symptomatic periods, patients may have a range of needs that could be met by caregivers, including assistance in making treatment decisions. When these episodes resolve, generally many of the associated functional impairments resolve and, with them, the need for caregiver support (2).
- For individuals with early life onset of mental illness, such as schizophrenia, the caregivers are likely to be parents, who will inevitably face problems associated with aging. Psychiatrists may be called upon to facilitate the transfer of caregiving from elderly parents to a patient's siblings, friends, or others.
- For individuals with late onset conditions, such as Major Neurocognitive Disorder due to Alzheimer's disease, caregivers are likely to be spouses or children. Psychiatrists may be called upon to monitor the effect of caregiving on the aging spouse or overwhelmed children to ensure that they remain capable of meeting the substantial demands of this very challenging role (3).
- Each patient requires an individualized assessment of the need for caregiver assistance. Psychiatric diagnoses vary widely in associated symptoms, impairments, and disabilities. Even within a given diagnosis, there is substantial heterogeneity of symptoms and impairments. Many patients will not need caregiver involvement; others will need substantial support.
- Individualized assessment is also necessary to address the many complexities arising from psychiatrist-patient-caregiver relationships. Some patients will welcome the involvement of caregivers, but others will not. In some instances, patients will not recognize their illness or need for treatment. This lack of awareness may afflict a high proportion of individuals with schizophrenia and bipolar disorder. As a result, some patients may have longstanding conflicts with their natural caregivers. These conflicts may be exacerbated

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by cognitive impairments and may have become the focus of delusional beliefs. Psychiatrists may have great difficulty repairing these schisms and negotiating more therapeutic relationships.

Ethical Considerations

Psychiatrists have an ethical duty to attempt to provide effective care to their patients. Providing effective care requires acquiring the information needed for developing an accurate formulation and making a correct diagnosis. It also often requires psychiatrists to engage persons close to the patient in the implementation of the treatment plan (e.g., in the supervision of medication use and in the making of appointments for follow-up). The adequate engagement of family caregivers is a necessary skill for all psychiatrists. Caregivers may need specific education and support to be able to fulfill their caregiving role. For this reason, among others, communicating with caregivers and involving them in treatment may be essential components of good care and ethical practice.

Psychiatrists also have a duty to respect the autonomy of patients. Respect for autonomy requires psychiatrists to give great weight to the wishes of their patients regarding the sharing of clinical information with anyone, including caregivers. Psychiatrists recognize the fundamental importance of protecting patients' confidentiality. Without the expectation of privacy, patients may not share essential information or engage in treatment at all. For this reason, among others, respecting the wishes of patients regarding the sharing of information with caregivers is an essential component of good care and ethical practice.

It is clear that the question of sharing information with caregivers may present the treating psychiatrist with an ethical dilemma, i.e., a situation in which two important moral duties appear to be in conflict. Resolving ethical dilemmas usually involves delving deeply into the details of the case at hand for facts that identify the correct path. But in the cases involving the sharing of clinical information over patients' objections, psychiatrists also must take into account state and federal law and regulations.

Legal Considerations

Psychiatrists' interactions with caregivers generally implicate issues related to patient privacy and decision-making autonomy. When impaired, many patients may not be able to make decisions related to disclosing details of their psychiatric care (or other care), and may not be able to make treatment decisions. Caregivers play a critical role in assisting their loved ones to seek help and to find and authorize appropriate treatment. As will be discussed below, caregiver assistance may extend to providing legally recognized consent to psychiatric treatment and to receiving otherwise confidential information.

Privacy

Historically, the appropriate management of medical information has been addressed as a component of the physician-patient relationship. On the foundation of a general expectation of confidentiality, physicians elaborated professional standards for the disclosure of information. As with other professional standards, those concerning disclosure of information to caregivers and others were not reduced to written form; they were flexible, context-specific, and governed by the goal of acting in patients' best interests.

Today, in the United States, the privacy of healthcare records is protected by a complex set of federal regulations and state laws that complement and, in some cases trump, the professional standard of care.

HIPAA is a set of federal regulations that govern many, but not all, health care providers. The rules governing disclosures of information are elaborated in detail. The most straightforward approach to facilitating communication between psychiatrists and caregivers is to obtain written authorization from the patient. When this is not possible—for example, when the patient presents to an emergency room or inpatient unit for the first time, with no prior relationship established—HIPAA does provide for some flexibility. Recent guidance from the U.S. Department of Health and Human Services addressed some of the problematic issues concerning communications with caregivers (4).

In recognition of the integral role that family and friends play in a patient's health care, the HIPAA Privacy Rule allows these routine—and often critical—communications between health care providers and these persons. Where a patient is present and has the capacity to make health care decisions, health care providers may communicate with a patient's family members, friends, or other persons the patient has involved in his or her health care or payment for care, so long as the patient does not object. See 45 *CFR* 164.510(b). The provider may ask the patient's permission to share relevant information with family members or others, may tell the patient he or she plans to discuss the information and give them an opportunity to agree or object, or may infer from the circumstances, using professional judgment, that the patient does not object. A common example of the latter would be situations in which a family member or friend is invited by the patient and present in the treatment room with the patient and the provider when a disclosure is made.

Where a patient is not present or is incapacitated, a health care provider may share the patient's information with family, friends, or others involved in the patient's care or payment for care, as long as the health care provider determines, based on professional judgment, that doing so is in the best interests of the patient. Note that, when someone other than a friend or family member is involved, the health care provider must be reasonably sure that the patient

asked the person to be involved in his or her care or payment for care.

In all cases, disclosures to family members, friends, or other persons involved in the patient's care or payment for care are to be limited to only the protected health information directly relevant to the person's involvement in the patient's care or payment for care.

The HIPAA Privacy Rule permits the disclosure of information to avert a serious threat to health or safety (5). Under this provision of HIPAA, a psychiatrist, acting in good faith, may use or disclose information when it is "necessary to prevent or lessen a serious and imminent threat to the health or safety of a person or the public." Disclosures under this provision may be to persons "reasonably able to prevent or lessen the threat" and may include the "target of the threat." Caregivers may be in a position to intervene; they may also be targets of threats.

State laws may provide additional protections of patient privacy and, in some states, may provide further definition of psychiatrists' duty to avert harm to others (6). Psychiatrists are advised to be conversant with state laws as well as policies and procedures in their specific practice settings.

Consent

Consent to treatment is governed by the doctrine of informed consent. In order to provide informed consent, a patient must be competent. In emergency circumstances, generally when there is imminent risk of harm to self or others, treatment may be provided without consent.

With respect to psychiatric inpatients, state laws vary. In many states, a patient who refuses treatment may be treated involuntarily only with judicial approval and oversight. This is often based on a judicial determination of incompetence. In other states, confirmation of the need for treatment may suffice as the basis for treating an objecting patient, and administrative or clinical procedures may suffice. Generally, more stringent legal proceedings govern the provision of electroconvulsive therapy over a patient's objection.

In some states, the law governing outpatient treatment of incompetent or objecting patients is the same as that for inpatients. In other states, a legal guardian or a caregiver recognized by state law may be able to authorize treatment.

Once again, psychiatrists should become familiar with the law and policies governing their local practice setting.

Advance directives (ADs), including psychiatric advance directives (PADs), are used to facilitate the treatment of individuals afflicted with serious mental disorders (7). ADs include instructional directives regarding treatment (sometimes called living wills) and proxy directives (also called durable powers of attorney) that designate caregivers to make decisions. ADs may be useful in a number of ways:

1. To facilitate treatment of patients before hospitalization is necessary.
2. To provide advance authorization for hospitalization when patients lack capacity to consent.
3. To facilitate the provision of treatment to refusing patients during hospitalization.
4. To provide evidence of valid consent for patients who accept medication while symptomatic.

ADs may be used to provide explicit authorization to specified caregivers to have access to confidential information and to make treatment decisions. ADs may reduce reliance on formal legal procedures, such as civil commitment and guardianship, which may lead to adversarial relationships. These legal mechanisms are expensive, often lead to delayed treatment, and may alienate patients.

Recommendations for Psychiatrists

Beginning Treatment: Obtaining a History of Caregiver Participation

The treating psychiatrist should assess the role of caregivers in their patient's life at the outset of treatment (8).

- At the time of evaluation, psychiatrists should consider the past and current roles of caregivers in the patient's life.
- Obtaining information about caregivers will flow from the routine evaluation process. In gathering information about the presenting problems, history of present illness, and past psychiatric history, the psychiatrist will learn about significant impairments and disabilities. Patients who have had past impairments will likely have a history of support and intervention by family and loved ones. Important information about past and potential caregivers will be obtained in the process of obtaining family and social histories.
- When caregivers have been involved in the past, or are involved currently, the treating psychiatrist will gain useful information by inquiring about the nature of the caregiver participation. It may be useful to review each caregiver one-by-one. How did the caregiver participate in the past? How is the caregiver currently participating? Was the patient satisfied with the caregiver and the ways in which support was provided? What worked well? If there were problems, what could be done differently in the future?
- With the patient's authorization, the treating psychiatrist will often find it useful to gather information directly from caregivers past and current. The history gathered from the patient and the caregivers will provide the psychiatrist with insight into the nature of the patient's past and current impairments. This often will aid the psychiatrist in the formulation of a treatment plan to address symptomatology contributing to

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impairments, to arrange for needed rehabilitative and support services, and to involve caregivers in the patient's care.

Planning for Caregiver Participation

The treating psychiatrist should develop a plan for caregiver involvement when appropriate. The psychiatrist should strive to develop a plan that clarifies the roles of caregivers, facilitates optimal communication, and results in effective treatment. The process of developing the plan should draw all parties together and lead to a shared understanding regarding respective roles in the care plan and caregivers' access to information. The development of the plan should strengthen caregivers' commitment to the therapeutic process.

- The psychiatrist's judgment about future a patient's need for caregiver assistance may be based on past patterns of illness, current functioning, and prognosis. The treating psychiatrist may determine that some patients have an immediate or inevitable need for caregivers. In other cases, the need for caregiver planning may be less obvious, but may be prudent nonetheless.
- In some cases, the psychiatrist may conclude that the history and likely clinical course do not indicate a need for formal planning regarding caregiving.
- In some cases, the treating psychiatrist will find it useful to discuss caregivers' participation with the patient and to create a caregiver plan (CGP). The treating psychiatrist should initiate a discussion with the patient regarding their caregiver preferences and the likely future need for caregiver involvement in care.
- The treating psychiatrist should document the CGP in the progress notes or elsewhere in the patient's chart. The psychiatrist should briefly describe the essential elements of the plan agreed to by the psychiatrist, patient and caregiver.
- The psychiatrist, patient, and identified caregivers should work together to formulate the caregiver plan. A CGP would identify individuals who will be involved in the patient's care and the nature of their involvement. Based on the patient's diagnosis, history, and prognosis, the psychiatrist will be able to estimate likely future impairments and areas in which caregivers' participation may be useful.
- A CGP should identify a caregiver or, in some cases, a set of caregivers, and specify their participation.
- What if there are no obvious caregivers? It may be necessary for the treating psychiatrist to assist the patient in identifying caregivers, particularly if there is an immediate or likely need. In some instances, patients will have become alienated from parents and other family members, perhaps as a result of their illness. The treating psychiatrist may be able to facilitate a rapprochement. Local religious and other charitable organizations may provide resources and caregivers.
- A CGP may cover a range of issues including housing, income support, transportation, care of family members, as well as clinical issues. Attention to the emotional and practical needs of the caregiver is also important.
- Caregivers may provide assistance in identifying onset of illness, initiating treatment (emergent, urgent, or routine), accompanying the patient to treatment sessions, and assistance in complying with treatment (obtaining medication, organizing administration at prescribed intervals, etc.). They are frequently excellent sources of information about the status and progress of patients and essential partners in the implementation of the treatment plan.
- Caregivers may be able to identify triggers to the onset of illness that the patient does not recognize or accept.
- A CGP will usually include an understanding about information sharing with one or more caregivers. It may include a formal authorization of information disclosure by the patient. Formalizing may be essential when other systems are likely to come into play; for example, when an outpatient may be hospitalized.
- Regular communication with caregivers may be useful. This may be done in a variety of ways: in person, by phone, by email. In some cases, it will be advantageous for the caregiver to accompany the patient to some, if not all, psychiatric visits. Caregivers often have observations about the patient's level of functioning, symptoms, and adaptation. These observations may serve to provide early warning regarding the onset of significant illness or the emergence of side effects to medications. For some patients, communication with caregivers may be an essential element of the CGP. For example, some patients with Bipolar Disorder will not recognize the onset of symptoms or related problematic behaviors. Caregivers' observations may be useful adjuncts to the psychiatrist's mental status examination and office-based assessment of functioning. In some cases, they may be essential.
- The CGP may also provide a plan for how decisions about care are to be made in the event that the patient becomes impaired. In some cases, a CGP may include an Advance Directive (AD) (e.g., proxy directive or durable power of attorney) that facilitates decision-making by a designated caregiver. ADs may also be used to authorize the release of confidential information.

- When possible, the caregivers should be involved in the development of the plan. Caregivers' involvement serves to establish lines of communication to the psychiatrist and to provide a foundation for the development of a relationship between caregiver and psychiatrist. The development of the plan as a shared project will serve to facilitate communication among the parties, to ensure that everyone has the same expectations, and to settle logistical issues related to communication and response in the event of emergent clinical or other issues. Discussing and anticipating potential problems may be therapeutic and facilitate commitment to treatment goals.
- Caregiver participation in a patient's care need not be driven entirely by current impairments or the prospect of future impairments. Some patients simply prefer to have loved ones involved and knowledgeable about their care.

When a Crisis Occurs: Implementing the Caregiver Plan

Implementing a plan at the time of a crisis poses a challenge to the therapeutic relationship. The treating psychiatrist should strive to maintain the therapeutic relationship, even when the patient disagrees about the necessary course of action. Following a crisis, the treating psychiatrist, patient, and caregivers should revisit the caregiver plan.

- Crises may arise in numerous ways, often with the onset or exacerbation of symptoms. Patients may fail to make office visits, or to respond to phone calls or other efforts to communicate. In some cases, a patient may disagree about the presence of symptoms and the urgent need for treatment.
- A clinical crisis may lead to a number of interactions between the treating psychiatrist and caregivers. Caregivers may provide information to the treating psychiatrist regarding the patient's behavior and symptoms. The psychiatrist may enlist caregivers to support clinical interventions for the patient's welfare, such as to add medications, change dosages, or meet more frequently.
- Based on the emergence of cognitive impairments, the treating psychiatrist may judge the patient to have doubtful competence. Generally, the treating psychiatrist will try to resolve the therapeutic impasse (non-compliance with medication, refusal to enter the hospital) without resorting to legal interventions (court orders, involuntary civil commitment). Caregivers may play an important role in these clinical interventions.
- At times, however, it may be necessary for the psychiatrist to invoke formal interventions, which may include applying the directives from PADs or invoking legal procedures (involuntary civil commitment, court

ordered medication). Caregivers should be involved in the decision-making process when possible.

- The treating psychiatrist should continue to pay close attention to the therapeutic relationship. In some cases, it may be useful for the treating psychiatrist and caregivers to make reference to the caregiver plan in their discussions with the patient.
- The treating psychiatrist should continue to discuss therapeutic decisions with the patient, even when caregivers have assumed the role of legal decision maker. The treating psychiatrist should strive to involve the patient in planning to the greatest possible extent, anticipating the patient's recovery of functional decision making capacity.
- After the resolution of the crisis, when the patient has resolved acute symptoms and impairments, it may be useful for the psychiatrist to review the episode. A discussion of the actions taken by the psychiatrist and caregivers in accordance with the CGP may facilitate greater insight.
- Also, it will be useful for the psychiatrist, patient, and caregivers to revisit the CGP plan. What worked? What did not work? What additions and changes should be made?

When a Crisis Occurs in the Absence of a Plan

The treating psychiatrist may receive information from caregivers. They may also convey information to caregivers with some limitations. The treating psychiatrist should strive to involve caregivers and note the need for a future caregiver plan. Legal mechanisms may need to be invoked in order to provide care.

- A crisis may develop in the absence of a caregiver plan. There may be no signed authorizations to disclose information, and no prior relationships with caregivers or the patient.
- Caregivers who are family and friends (not health care providers) are free to communicate information to the treating psychiatrist.
- If the patient is regarded as having capacity to make health care decisions and is present, the treating psychiatrist may communicate with caregivers as long as the patient does not object, according to HHS guidance regarding HIPAA (see above).
- When a patient is not regarded as having capacity, or is not present to register an objection, the treating psychiatrist may share information with caregivers if it is in the patient's best interests.
- in some cases, the treating psychiatrist may need to seek out alienated family members in an attempt to engage them in the patient's care.
- Regarding treatment, it may be necessary for the treating psychiatrist to employ legal procedures to

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hospitalize the patient. And, if the patient refuses necessary treatment, the treating psychiatrist may have to invoke involuntary treatment processes.

- Prior to discharge, it may not be possible to develop a caregiver plan for future episodes. It would be useful to suggest development of a caregiver plan to the outpatient psychiatrist accepting responsibility for the patient's care.

Other Caregiver Issues

The treating psychiatrist should be alert for emerging problems in caregivers.

- The treating psychiatrist may find that a designated caregiver is not able to fulfill their planned role. This may occur as occur as a result of competing obligations or commitments to work, family, or other interests. Caregivers may also develop psychiatric or medical problems that affect their ability to function as planned. Being a caregiver is stressful and may precipitate or contribute to emotional distress. The treating psychiatrist should be alert for emerging emotional problems in caregivers and make appropriate referrals as necessary. Regardless of the reason for the caregiver's inability to act in their planned role, the treating psychiatrist should have the patient designate another caregiver or decision maker.
- Caregivers may have goals or interests related to the patient's care and management that are not compatible with those of the patient. These conflicts may not be evident at the outset of treatment. One example is when children serving as caregivers and surrogate decision-makers are also heirs and may experience a conflict of interest in decisions about how to use the patient's financial assets. The treating psychiatrist should discuss conflicts with the patient. Many conflicts may be resolved through open discussion with the patient and caregiver. In other cases, it may be necessary to change or eliminate the caregiver's participation in the patient's care and management.

- Some patients may have multiple caregivers. This is often the case when caregiving for an elderly parent with Alzheimer's disease is shared by several children. At times, caregivers will disagree about the appropriate course of action. The potential for conflicts may be kept to a minimum when the patient makes their preferences clear in advance of a crisis. In some instances, for example when there are several family members involved, it may be useful to have a primary caregiver designated to interact with the treating psychiatrist.

REFERENCES

1. Mitnick S, Leffler C, and Hood VL, for the American College of Physicians Ethics, Professionalism and Human Rights Committee. Family caregivers, patients, and physicians: ethical guidance to optimize relationships. *J Gen Intern Med*, 25(3): 255-60, 2010.
2. Of course, other patients have chronic impairments and, as a result, may have an ongoing need for caregivers' assistance. Those with progressive neurocognitive disorders may face a predictable increase in the need for caregivers' assistance.
3. In this document, we do not specifically address the needs of caregivers or the family system, although we acknowledge that these must be addressed for optimal patient functioning.
4. HIPAA Privacy Rule and Sharing Information Related to Mental Health, available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/mhguidance.html>
5. HIPAA Privacy Rule, Section 164.512(j).
6. For further information regarding psychiatrists' duties to protect third parties, see APA Resource Document on Physician's Duty to Take Precautions Against Patient Violence, 1987.
7. See Psychiatric Advance Directives, Resource Document, approved May 2009, American Psychiatric Association. Available at http://psychiatry.org/File%20Library/Learn/Archives/rd2009_AdvanceDirectives.pdf. Additional resources are available at the National Resource Center on Psychiatric Advance Directives, <http://www.nrc-org>
8. The treating psychiatrist may be acting as the head of team and may delegate various functions to team members.