

Serving as a Patient Advocate

The goal of a patient advocate program is to train people to work on a one-to-one basis with older adults and others who need assistance managing chronic illnesses and medical conditions. The primary responsibility of patient advocates is to serve as an extra pair of eyes and ears when patients are interacting with their physicians, facilitating the flow of information between patients and physicians. Once medical information has been exchanged, patients often need assistance in following their physician's recommendations. For example, patients often find it difficult to remember follow-up appointments or to consistently comply with their doctor's recommendations about medications. Patient advocates can help patients organize their schedules and medicines and then provide further assistance by telephone or brief visits. Also, they can discuss with patients steps to prevent additional medical problems (e.g., injuries resulting from falls) and how to maintain control over decisions about their medical care if they become incapacitated (e.g., use of advance directives). Patient advocates can provide emotional support and reassurance for patients. However, they should not be expected to provide any financial support, nor are they to receive any financial benefits.

Although the time demands on patient advocates do not have to be great and the training required is not extensive, several special qualities are necessary to serve in this capacity.

- **You must be willing to listen and talk about difficult issues.** Some of the things you may hear about and discuss with patients and physicians may not be pleasant, yet these matters must be dealt with openly and professionally to facilitate the best possible care for the patient. Furthermore, patient advocates often are entrusted with sensitive information that must be treated with *absolute confidentiality*. You must understand and accept this responsibility. The information you hear cannot be shared with anyone other than the patient unless you are clearly instructed to do so by the patient.
- **You must be able to earn the trust of both patients and medical professionals.** Although we can provide individuals with the knowledge and skills to serve as patient advocates, your effectiveness will be greatly limited if you do not have the trust and respect of patients and health care providers.
- **You must be able to respect not only the patient's privacy but also his or her wishes.** You may encounter situations in which the wishes or values of the patient conflict with your own. In these situations, you must be willing to set aside your own feelings and act on behalf of the patient. It is your responsibility to act as the agent or representative of the patient.
- **You must not bring your own personal agendas regarding medical care into your work.** The role of the patient advocate is to serve as a facilitator, not as an adversary of physicians, nurses, or hospitals. Although you may need to be assertive and persistent in some of your efforts, you still need to feel comfortable about working within the health care system.

You will need to establish good working relationships with the patients you are assisting. This is usually a two-step process: The first step is developing rapport with the patient; the second step is clarifying your role as a patient advocate.

Developing Rapport with the Patient

Begin by saying a few things about yourself (e.g., your previous work experience or some of your current activities). Although you should disclose enough information about yourself so that the patient feels comfortable with you, do not go into too much detail. Keep the focus on the patient and his or her needs. As you talk with the patient, try to create a relaxed atmosphere. Let the patient see that you are comfortable talking about health matters and personal concerns.

Clarifying Your Role as a Patient Advocate

As you develop rapport with the person you will be assisting, suggest that it would be helpful for you to explain specifically what you will be capable of doing as a patient advocate. Let the patient know how you envision your role.

- *Address the issue of confidentiality.* Even though a patient advocate might have good intentions about sharing information (e.g., encouraging others to provide assistance), such disclosures can undermine, and even destroy, the relationship between the patient and the patient advocate. Therefore, it is imperative that you treat all information as absolutely confidential. Only if the patient clearly gives you permission to share personal and medical information should you do so. You should take the initiative in discussing this issue because some patients may be reluctant to say anything about it even if they have concerns.
- *Clarify your limitations.* You should be certain that the patient realizes that you are not a medical expert. You should not be expected to be the direct source of information or advice about medical matters. Instead, your role is to help the patient obtain the necessary information from physicians and other appropriate sources.
- *Clarify financial matters.* It is not the role of a patient advocate to provide financial support for the patient. If the patient has financial problems that interfere with his or her ability to obtain recommended treatment, you may help him or her bring this to the attention of the physician, hospital social worker, or an appropriate social service agency but you should not be expected to provide or find sources of money yourself.

Another financial matter to be addressed is the issue of a patient advocate receiving money or gifts for his or her efforts. This may be an unspoken concern of the patient's family members who are not close enough to monitor your activities. They may fear that you will obtain control over the patient's bank account and misuse the money. It is best to address this fear by suggesting that the patient contact relatives and explain your role as a patient advocate.

After you feel you have established rapport with the patient and given him or her enough information about your background, your interest in the program, and what can be expected of you, you are ready to begin gathering information about the patient's medical concerns and any related matters. The questions presented in *Making the Most of Your Medical Visit* can serve as a guide. A patient check sheet and a patient information sheet can be used in preparation for the meeting with the doctor.

The patient check sheet can guide you as you talk with the patient. In most cases, this form does not need to be taken to each appointment. The information you gather as you complete this form can be concisely summarized and transferred to the patient information sheet. However, as you fill out the patient check sheet, if you discover that there have been several significant changes in the patient's life since his or her last doctor's visit, it may be best to take this form with you.

The patient information sheet is designed to be completed before the appointment and taken to the meeting with the doctor. This sheet can help you organize the information the physician needs and establish a prioritized problem list.

As you talk with the patient, do not hesitate to speak up if you are confused by something the patient has said. If you do not understand a term or are uncertain about what the patient means, tell him or her that you are confused. This will let the patient know that you are genuinely interested in understanding what he or she is saying.

If the patient expresses a sense of loss or emotional pain related to his or her illness, do not try to provide immediate relief or reassurance. Give the patient ample opportunity to talk about fears or losses. The danger of offering reassurance too quickly is that the patient may think that you do not understand his or her feelings or do not even wish to.

Do not rush to fill silent periods in your conversations. Give the patient time to think and respond. Silent periods can be valuable to both of you. He or she may need time to reflect on some issues you have raised, and you can use these periods both to review what has been discussed thus far and to observe the patient's nonverbal behavior. If you think the patient's eyes or facial expression reveals a certain emotion, share your observations. For example, if you think you detect fear, gently ask if this is what he or she is experiencing.

Finally, try not to be surprised or shocked by the unexpected. You may assume that the patient feels a certain way because that is how you would feel or because you know how other people have reacted under similar circumstances. Although it is helpful to draw on your own experiences or those of others, recognize that not everyone reacts in the same manner.

When you and the patient have finished preparing for the visit to the doctor, you need to discuss what your role will be at the doctor's office or hospital. Some patients will want you to accompany them into their meeting with the doctor to assist them in explaining their concerns and help them record the doctor's explanations and recommendations. In these situations, it is advisable for you or the patient to explain to the doctor who you are and why you are there. Also mention that you will excuse yourself during the physical examination but that you would like to be brought back into the meeting so that you can hear the doctor's recommendations.

A form entitled “Summary Form for Physician Visit” can be used for recording the doctor’s explanations and recommendations. Because the goal of recording the doctor’s recommendations is to facilitate the accurate and complete exchange of information, it is important that you ask the physician to review and confirm what you have written down. Have the doctor initial the form on the line at the bottom.

Another way you can assist the patient is to encourage him or her to be assertive in expressing concerns to the doctor. Many patients find it difficult to be assertive with their physicians. Some feel that it is disrespectful to question the doctor’s opinions and recommendations or to offer information that is not specifically requested. Instead, these patients adopt a passive role, allowing their doctor to ask all the questions and set the direction for discussion. They see their doctor as the source of all knowledge and expertise. Other patients are skeptical of their doctor’s advice, but they do not share their feelings directly with the doctor. They keep their opinions to themselves during their appointment, but once they leave, they disregard the doctor’s recommendations.

Although it may seem obvious that patients need to express themselves while meeting with their physicians, it is not easy for some people to be assertive, especially with authority figures who seem to be so knowledgeable. It is important for patients to realize that they also possess valuable expertise when the subject is their own health. They need to remember that they have important information that needs to be communicated to their physician and that good, comprehensive care can be provided only when they share this information. Gentle reminders from you can help patients become more confident and assertive.

As a patient advocate, you can play a valuable role in helping patients benefit from the medications that have been prescribed. In fact, physicians consider this one of the most important roles for patient advocates. Here are several suggestions you can follow to improve patient compliance with taking medications:

- Ask the patient, “Do you understand why your physician has prescribed the medication?” The patient should know what the medication is for, how to take it, and what to expect. If the patient does not understand why the medication was prescribed, encourage him or her to check with the physician.
- Write down the information and instructions provided by the patient’s physician. Take notes while you are in the doctor’s office. Space is provided on the “Summary Form for Physician Visit.”
- Encourage the patient to ask his or her primary care physician to review all the patient’s medications. Suggest that the patient take all his or her medications, or at least a list of the medications, to the doctor’s appointment. Include over-the-counter (nonprescription) drugs and nutritional and herbal supplements.
- Advise the patient to report any unexpected or unpleasant side effects to the doctor.
- Suggest that the patient use one pharmacist or pharmacy for all his or her medications and encourage the patient to accept medication counseling when it is offered by the pharmacist.
- Advise the patient to ask his or her pharmacist to contact the doctor when a medication is too expensive. A less expensive alternative may be available.
- Encourage the patient to use medication organizers or pillboxes.

- Help the patient keep a record of his or her medications. The record should include information about the medication, what it is for, color and shape, the time it is to be taken, any concerns or problems related to it, and how regularly the patient takes it as prescribed.

Most important, encourage the patient to communicate openly with his or her physician about medications. The patient should not hesitate to ask questions or report difficulties with the medication.