

The California Patient's Guide: Introduction

Appendix D

Strategic Advice For Patients: Tactics to Use and Understand

The patient denied treatment often finds oneself in an adversarial system. Your tactics must be those of negotiation.

Everything is negotiable--with the HMO, the HMO doctor, the HMO hospital. In a negotiation, establishing what is reasonable is the goal.

- What should a reasonable person have to do in order to document his or her need for treatment?
- What should a reasonable corporation have to provide and how long should it take?
- Is the company living up to the letter and spirit of state and/or federal law?

These are the types of standards someone negotiating with his or her HMO or HMO doctor must fight for.

Often HMOs do not concede expensive treatment without constant and repeated demands. Enough delays will equal a denial for a patient in need of critical care.

Reasonableness always includes a reasonable timetable. When will a decision be made to approve the care? Who is the decision-maker? How long will it take to schedule the procedure? What is the longest it will take before this doctor sees me?

The tactics of getting care from an HMO or HMO doctor may be no different than those involved in any other struggle against bureaucratic power. The major difference is that the patient is typically not in any condition to fight. That is why others close to them must take on that role. Patients themselves should make such contingency plans.

There are also some general rules one can always follow in dealing with HMOs, but these are no panacea, simply precautionary measures.

* **Write everything down.** Bring a notepad and pencil to all medical facilities and take notes on what your doctor tells you. This may feel uncomfortable, but it will help to keep track of your care, catch any errors, and provide a record should there be a question of inappropriate treatment. Also, write down the name of anyone you speak to on the phone, date the conversation occurred, and the outcome

* **If you are denied care, ask for it in writing.** You will need a record of the denial if you want to dispute it. Memorialize in written correspondence all conversations if it becomes apparent that you are not receiving cooperation. Leaving a "paper trail" often helps to get results.

* **Find out the timelines.** There are many state regulations establishing the timeframe within which a treatment or coverage decision must be made (see sections VI and VII of this guide) Make sure everyone you deal with at the medical group or the HMO know that you know what those timelines are and make sure they stick to them. Also, as part of their marketing, most HMOs are accredited by non-government groups such as National Committee for Quality Assurance [www.ncqa.org], American Accreditation HealthCare Commission/URAC [www.urac.org] and the Joint Commission on Accreditation of Health Care Organizations [www.jcaho.org]. These organizations often have timeline requirements even more stringent than the state requirements. Find out if your HMO is a member of any of these organizations and if it is, find out that organization's timeline requirements for the health plan's decision-making process. Again, make sure the HMO knows that you know those timelines and that you expect them to be followed.

* **Complain to the accrediting organization.** Because HMOs rely so strongly on their accreditation by the non-governmental organizations (NCQA, URAC and JCAHO) in their marketing to employers and unions, they dislike having complaints documented to those groups even less than they like having complaints on file with government regulators. In addition to copying your documentation to the state regulators, copy it to the accrediting organization or organizations that your HMO is a member of.

* **Find allies in the medical profession.** When medical experts advocate care, HMOs find it harder to deny treatment. Insist on a second or third opinion--from a qualified professional outside the HMO network, if necessary. If your HMO won't pay for a second opinion, pay out of your own pocket. It could save your life.

* **Ask how your doctor is paid.** Medicare recipients are entitled to see a summary of their physician's contract with their HMO, which details any financial incentives to withhold treatment. Doctors should increasingly provide such information to all patients. File a complaint with your state's medical board if you believe your doctor is withholding treatment for his or her own pecuniary gain.

* **Never take "no" for an answer.** Always ask if there are treatment options available for you other than those the HMO recommends. If you have a problem, take it up the ladder--fast. Enlist the help of your employer's personnel department if you get your health care through your work.

* **Never stay in a hospital by yourself.** Have a spouse, loved one or friend present at all times when you are in the hospital, even if that means sleeping in a chair. Having an advocate present to monitor what is happening around you, to make sure you get the treatment you need, is essential. If something goes wrong, he or she can act quickly to secure assistance.

* **Do not be intimidated.** Do not permit yourself to be intimidated by someone else's uniform, occupation, credentials and stature. You're paying the bills, not only as a consumer, but also as a taxpayer who helps fund the medical system. Write and call everyone you can think of in the HMO--the CEO, the Medical Director, the President of Marketing, the Board of Directors and the [Ombudsman](#). Contact your elected representatives for help. Write the newspapers. Enlist your doctor as an advocate for you whenever possible (good doctors will put aside any conflicts of interest to protect your health). Enlist your employer if you get your health care through your work.

But always maintain a reasonable, professional and calm demeanor, both in person and in writing--no matter how hard that is to do sometimes. If you lose control, make threats of violence or use foul language, you will simply be dismissed as a "crank," "flake," or "weirdo," and you will not accomplish your goal.

* **Get a lawyer if you need one.** Lawsuits are no fun. They can take years, involve endless and grueling maneuvering. Most who go through the process say they underestimated how hard it would be, especially to relive the medical trauma. And then, of course, there is the possibility that you have a legitimate case but will be unable get it into court, or prove it once you're there.

Patient Advocate Primer: Persuade, Plan, Passion, Pin

To be an effective advocate for yourself or someone else, there are a host of principles you can follow and many excellent books on the methods of advocacy. But here is a primer.

Persuade

The most effective advocate is the most persuasive. Persuasion is the goal of all advocacy.

Persuasion is the goal of the written word, the spoken word, unspoken messages. The right words or action from the right person or people to the key decision-makers at the appropriate time is the equation for success in advocating any position.

A series of small victories at being persuasive equals a successful campaign.

Get the right doctors on your side who will then write to the correct medical director with the appropriate language and you are more likely to get care.

Perhaps one doctor is a stumbling block to you getting appropriate treatment. This physician may have a financial incentive (capitation) not to refer you to a specialist or for a test, because the money for these procedures comes out of the doctor's own pocket. Ironically, in this case, the HMO could be one important ally. If the HMO is not paying for the treatment, since the risk is shouldered by the doctor, the HMO has no disincentive to helping you compel the doctor to provide appropriate care.

Plan

Being persuasive starts with forming a strategy.

Who is the right decision-maker? What words will most influence them and from whom? How much time should I give them to reply? These questions must be asked before mapping a strategy for action.

Effective advocates do not make a first move without forming a strategy. The first formation of a strategy is a clear identification of your goal and your obstacles. The goal should be as specific as possible, but it may require many goals to achieve a large one.

For instance, receiving a specific course of high-cost treatment may be your goal.

1. To achieve this you will have to map out much smaller goals.
2. Each of these smaller goals should have a timeline attached to them, leading up to the large goal.
3. Identify potential allies as well as obstacles.

MAIN GOAL: Proton-beam therapy to start by January--referral from medical group for out-of-network treatment.

OBSTACLE: Primary Care Doctor X and His Medical Group Do Not Want To Make Referral Because They Are Responsible For Treatment's Costs But No Qualified Specialist Exists Within Medical Group

ALLIES: Government regulators; the HMO (it is not paying for the treatment because it passed full risk to the medical group, so it might as well help you get the care); the specialists out-of-network who will provide the care.

SUB-GOALS--MAP OF GOALS

First Goal: Letter From Specialist Physician To Medical Group Medical Director Asking For Treatment, Noting No Qualified Specialist Exists In Medical Group

Timeline: By Tuesday

Second Goal: Official Letter From Patient To Medical Group Asking For Treatment And Requesting A Response By Next Monday

Time Line: Today

Third Goal: File Preliminary Complaint with Regulatory Agency

Timeline: By Wednesday

Fourth Goal: Specialist Physician To Follow-up On Letter With Phone Call To Medical Group Medical Director

Timeline: By End Of Week

Fifth Goal: File Complaint with HMO's Customer Service Department

Timeline: By Wednesday

Sixth Goal: Have HMO Officer Call Medical Group About Treatment

Timeline: By End of Week

By creating a work plan and mapping your strategy, you can chart the advancement or stalling of your strategy and react appropriately. Your strategy map is a formula for what is reasonable. When it runs astray, you should react proportionately.

Passion

Passion is essential to any effective advocacy effort. When a loved one's life and death is at stake, passion tends to enter the equation. But your goals must always be to establish what is reasonable and not let your anger fog the vision of what needs to be done or keep potential allies from helping you. That is not to say that you should not communicate the urgency of the situation with every contact you make. You should. But you must be under control and maintain good human relationships. You should cultivate allies, rather than simply making enemies. Keep your dignity and composure even as you communicate a sense of urgency about the life and death stakes of the situation.

In dealing with a difficult medical situation, a balance of passion and reason is essential. It will also help keep key decision-makers to deadlines.

It is your job as a patient's advocate to set those deadlines for the key decision-makers.

Patient Advocate: We sent you the medical records Thursday, I am just following up to make sure you received them so you can issue the approval for my sister's treatment. As you probably know, she is in much pain and, as the letter attached to her medical records indicates, she must receive this treatment immediately.

Administrator: I have received the paperwork, but it is going to take a little while to process. The medical director has not yet reviewed it. I do not know that he has everything he needs to make a decision. But we will call you as soon as he reviews it.

Patient Advocate: What is the name of the medical director who is making this decision?

Administrator: It will either be Doctor Green or Doctor Yellow.

Patient Advocate: How soon will Doctor Green or Doctor Yellow be reviewing the file?

Administrator: I cannot say. We understand the urgency of the situation and will do this as soon as possible.

Patient Advocate: My sister is in so much pain. I need to give her a timeframe. What is your deadline for making this decision?

Administrator: I am certain they will look at the files this week, but they may need additional information, or to talk to the doctors involved. They will certainly begin the process this week. If they have everything they need, I am sure the decision will be made soon.

Patient Advocate: May I speak to Doctor Yellow or Doctor Green?

Administrator: They are not available. They are in a meeting. They will get to your sister's file as soon as they can, ma'am. Please be patient.

Patient Advocate: I understand you are all very busy. I just would like a timeline for this decision so I can talk with my sister about her options. You understand, don't you?

Administrator: Of course.

Patient Advocate: Can you give me a timeline?

Administrator: I am sorry, ma'am. I can't.

Patient Advocate: I am sorry, your name was Debbie ____.

Administrator: Debbie Red.

Patient Advocate: And who is your Supervisor?

Administrator: Dr. Orange.

Patient Advocate: And who is Doctor Yellow and Doctor Green's Supervisor?

Administrator: Dr. Orange.

Patient Advocate: Is Dr. Orange available?

Administrator: Let me transfer you to his Secretary.

Patient Advocate: Before you do that, will you please leave a message for Doctor Green or Doctor Yellow, whichever will take care of this file, to call me.

Administrator: Yes, ma'am. I have your number. Let me transfer you to Doctor Orange's office.

Pin
"Pinning" is the art of getting a timeframe for a decision and working through the hierarchy in this or any other organization. To pin is to narrow a commitment, a timeframe, a decision. You pin someone down to either get a commitment or more information that will lead to a commitment from a decision-maker. It is especially helpful in this scenario to know what the timelines are that are established by the appropriate state regulations or the applicable accrediting organization. Communicate to the administrator that you know what those timelines are

and that you expect them to be complied with.

The commitment is, of course, the goal of what you are pinning for but in some conversations it will be impossible to get a commitment because you are not speaking to a decision-maker.

Chain of Command

Every hierarchy has a chain of command. HMOs are nothing if not hierarchies. If a customer service representative cannot help you, talk to his or her supervisor immediately. If the supervisor cannot assist in the timeframe necessary, contact his or her boss, the division head, the medical director, the chief executive officer. Go as far up the chain of command as fast as possible. People make decisions most effectively when they feel that making the wrong decision will jeopardize their position.

Finding the chain of command and utilizing it is the modus operandi of pinning down a decision in the corporation. You must remember who you are talking to and the purpose of your conversation. The so-called administrator in the above example was not a decision-maker, but an "informer"--someone who could landscape how the company worked and what the chain of authority was. It would make no sense to argue with this employee about the details of the patient's condition, coverage or state law's requirements about covering the patient's condition. The purpose of this conversation was to find out who to write the letter detailing these facts to and putting the best case forward.

Know who you are talking to at an HMO. It makes no sense to argue your case before a bailiff, you must find the judge.

Sizing up an employee means a persistent but friendly conversation--pushing the limits of the conversation as far as they go, and gathering information. Persistence is the key to effective information gathering and pinning. Most people, however, are uncomfortable pushing the cusp of a conversation beyond what may be considered good manners. These are inhibitions which must be forgotten when an HMO jeopardizes a patient's health.

The documentation, research and advocacy you contribute to this process can help change things for the better for others. When all else fails, or does not appear to be succeeding in time, enlist others who can help even the balance of power between the patient and the corporation, such as the media. The level of what is reasonable that you help to establish for yourself or loved one will help clear access to care for those in the future.

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