



PACO

Patient Advisory Committee

Newsletter Spring 09
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Patient Centered Outcomes Initiative (PACO)
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Brigham and Women's Hospital, Rheumatology, Immunology, Allergy

Discussion with Kori Berardino, Practice Manager, Arthritis Center

During the February 26, 2009 PAC meeting, several patients commented on the "wait time" to see their rheumatologist, and the committee brainstormed ideas about what could be done. We invited Kori Berardino, Practice Manager in the Arthritis Center to our May 29, 2009 meeting to talk about "wait time" and other processes that affect patients in the clinic. Ms. Berardino oversees the clinic administrative processes and is particularly interested in patient concerns related to the Arthritis Center. She mentioned that there is a hospital-wide initiative to communicate patient wait time and improvement in the waiting areas.

In previous meetings, PAC members had said that wait times could vary, sometimes as long as two hours. Kori mentioned that it is hard to quantify an acceptable wait time across the hospital because some practices, like surgery, will be different if the doctor is in the operating room prior to seeing patients in the office. So the hospital-wide committee is asking each department to determine how best to communicate wait time to their patients. PAC members observed that someone should alert patients in a timely manner if their doctor is running behind. "It is very hard to call people in advance," Kori stated, "so the thought is that a patient would get an estimate at check in. That way if there was a wait, a patient could get coffee or do a crossword puzzle."

PAC members made a number of suggestions about how to improve the patient's waiting room experience. One idea was to tell patients when scheduling their appointment which times are less busy in their doctor's schedule. Kori said, "While this could be very helpful, it can unfortunately be hard to measure accurately when doctors will be busiest." A PAC member mentioned that she observed that the clinic is empty early morning. Patients might want to request an early appointment because the doctor will not be running late. Members also requested more arthritis focused reading materials in the waiting area.

The consensus was that it was extremely important for patients to be told if a doctor is running late and approximately how long the wait will be. Medical

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"A patient would get an estimate at check in. That way if there is a wait, a patient could get coffee or do a crossword puzzle."

Discussion with Kori Berardino (Continued)

assistants and receptionists can focus on this and be sure to keep all patients informed about their wait times. Some doctors try to come out to the waiting area and make contact with their patients to let them know they are running late. While long wait times can be frustrating, most PAC members agreed that a 30-minute wait was ok, and most did not experience wait times that were significantly long. The relatively new system of getting patients vitals read before their appointment has also helped to reduce wait times.

Another aspect of the hospital-wide initiative is to make the waiting areas clean and neat and with a good supply of reading materials. The addition of a T.V. in the waiting room was discussed, but most patients were not interested in this idea. Kori recently received a supply of "Arthritis Health Monitor" and hopes to maintain a variety of reading materials like "Time Magazine" and "People." There are often copies of "Arthritis Today" from the Arthritis Foundation. A PAC member mentioned the possibility of reading material donations. Although the intent is good, staff would have to be involved in monitoring materials, which would take time away from managing patient scheduling.



Ms. Kori Berardino (right) and PAC members discuss ideas about how to improve wait times in the Arthritis Center.



Dr. Shadick facilitates a discussion with PAC members

PACO Initiative

A collaborative effort between patients and researchers at the Brigham and Women's Hospital, funded by the Bristol-Myers Squibb Foundation



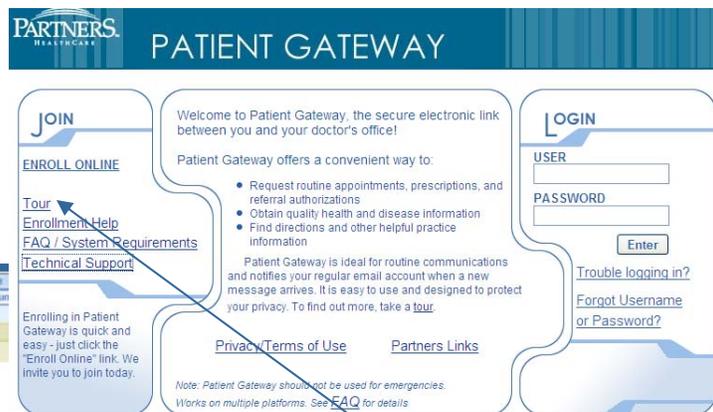
Patient Gateway – Online Access to medical information

At our February PAC meeting, there was some discussion of the Partners’ Patient Gateway. The Gateway is an online resource that Brigham and Women’s patients can use to access some of their health record information, change an upcoming appointment, request a prescription refill, or tell a doctor about side effects from a medication. Patient Gateway is “an application developed to provide patients with online access to their medical chart information, a health library, electronic form-based requests, and provider information. Seventy practices now offer lab results through Patient Gateway to more than 65000 patients. Patients can browse lab results and follow links to get additional information that explains what those lab results mean. Radiology results became available in June 2009. Thirty-seven practices have activated this feature. Patients can browse radiology report data and read text reports after a period of five business days, except mammograms, which are available immediately. Images are not yet available online, but patients can request them separately.” One patient commented, “I think it is great! I have checked my results, looked up the tests where I was outside the range to get an understanding. In addition to this, my doctor then sent me a letter through Patient Gateway with a summary of the key information. This Web access is great benefit!”

NOTE: Not all BWH doctors have adopted Patient Gateway, so please ask your provider whether s/he is using Patient Gateway. Patients can access and sign up for Patient Gateway at www.patientgateway.org/ On the home page, you can select “Take a Tour” or call 800-745-9683 for support.

Information for this article came from “Rounds” October 2009, an interview with Dr. Jonathan Wald, and an article “Patient Computing” <http://www.partners.org/cird/StaffPrj.asp?cBox=CurrProj&prAb=PCOMP>

“Patients can browse lab results data and follow links to get additional information.”



Take a Tour

Appointments, test results, messages



Summary of the Seminar on Sleep

Getting a good night's sleep is difficult when dealing with a chronic illness, so many patients requested that sleep be a topic of one of our seminars. On October 29th, 2009, Dr. Atul Malhotra, spoke on "*How to Improve Your Sleep: A Session for Rheumatoid Arthritis and Lupus Patients.*" Dr. Malhotra is a Pulmonary and Critical Care Physician who specializes in Sleep Medicine and is also the Medical Director of the Sleep Disorders Research Program, a group of about 50 people including doctors, scientists, technicians and students. The Sleep Program is one of only two Academic Sleep Programs of Distinction in the Country.

The seminar focused on addressing issues around poor quality of sleep and what patients can do to remedy this problem. Many patients complained of having trouble falling asleep, staying asleep through the night, and dealing with conditions such as sleep apnea. Poor sleep can greatly affect one's health. Sleep deprivation, which Dr. Malhotra clarified as sleeping only five hours a night instead of seven or eight, can result in increased weight gain, which can lead to more serious health complications, and increased risk of heart attack.

Many people with Rheumatoid Arthritis and Lupus deal with chronic pain that keeps them up all night, inhibiting them from having a good night's sleep. While many report that it is the pain that keeps them from sleeping well, recently doctors have started to think that the opposite might be true: that poor sleep causes increased pain the next day. Studies have shown that when people are sleep deprived their pain threshold is lower, meaning they are more sensitive to pain when they are tired. While no one may be sure which causes which, the pain or the poor sleep, focusing on getting better sleep may help reduce pain in the future. There may be other factors besides pain that cause poor sleep, like other sleep conditions or lifestyle behaviors. Treating or modifying some of these may help. In 1993 a study revealed that 4% of men and 3% of women in North America have sleep apnea. It is now thought that those numbers have increased because average body weight has increased in the past twenty years and being overweight is a risk factor for the disorder. There are two types of sleep apnea: obstructive sleep apnea and central sleep apnea. Obstructive sleep apnea occurs when the airway relaxes during sleep and obstructs breathing for a short period of time. Central apnea occurs when the brain's respiratory control center does not recognize fluctuating carbon dioxide levels and does not react quickly enough to create a smooth respiratory rate, resulting in missed breaths. Every time breathing is stopped, lungs are unable to perform normal air exchange, which causes oxygen to get low and carbon dioxide to build up in the blood. This stress on the body triggers the release of adrenaline to alert the body to get more oxygen. Overtime, the adrenaline builds up and causes increased blood pressure, which can lead to serious conditions such as heart disease. Some patients have been able to treat their apnea with masks that aid in the breathing process while sleeping. There are many different types of masks available and finding one that is comfortable may require some trial and error. However, finding a mask that works for you is beneficial as a mask can greatly improve sleep and health.



Dr. Atul Malhotra

Summary of Seminar on Sleep (Continued)

Many people have sleep issues, which have nothing to do with sleep apnea, such as difficulty falling asleep. Patients raised the question of whether it was good to use sleeping pills. Older sleep medications, such as valium, can be addictive while newer medications are not. Behavioral therapy may also be effective in helping to fall asleep. A randomized trial assessing sleeping pills versus behavioral therapy showed that they had almost equivalent success rates. Which one to use is based on personal preference, and many patients use both with great success. However, sleeping pills will not cure sleep disorders and may only hide other conditions. Thus, pills should always be prescribed by and closely monitored by a physician.

There are also natural remedies available that are marketed to help people fall asleep, such as melatonin. Melatonin is a hormone that regulates our bodies' circadian rhythms. It can be effective in helping shift our body clock so that we can fall asleep at a different time. However, it should not be considered a sleeping pill that will help a person fall asleep at the usual time. Many people find melatonin useful when travelling and changing time zones. Others reported using calcium before bed to help get to sleep, but unless you are calcium deficient, adding more will not do any good. Some other dietary remedies can help with sleep. Reducing alcohol and caffeine intake, and quitting smoking can help people get to sleep and sleep better throughout the night.

Even with all the above treatments and lifestyle changes, many people have trouble sleeping through the night, are tired the next day, and need to take a nap. For patients with chronic illnesses, resting during the day is often recommended particularly because side effects of some medications cause fatigue during the day. Dr. Malhotra recommended napping only for those who have no problem falling asleep later in the evening because it can make it difficult to fall asleep at night. For those that are tired during the day but napping would keep them up at night, Dr. Malhotra suggested exercise at the right time of day. Exercising when you would normally get fatigued can give a boost of energy and help with falling asleep at night. Some find exercising in the morning helpful while others found at night was best. However, Dr. Malhotra cautioned that exercising in the evening increased energy levels, which could make falling asleep more difficult. Experimenting with different times and different types of workouts, such as swimming (which can be easier on joints) versus jogging, can affect sleep habits. Finding your own right type and time of exercise can help cure some of your sleep problems.

While sleep problems plague many people, feeling exhausted and awful all day because of a bad nights sleep is not normal. It can lead to serious health conditions later on and disrupt daily activities. Dr. Malhotra encouraged people to talk to their doctors and/or set up an appointment at his sleep clinic (phone 617-783-1441). It is extremely important to seek out solutions to whatever is causing poor sleep habits because the most motivated patients usually have the best results.

Next PAC Meeting - November 6, 2009

Friday from 12:00 - 2:00pm

Location - Bayles Conference Room