

I Have So Many Doctors ... Whom Do I Call?!

A Patient Interviews an Associated Disease Specialist on Coordinating Care among Doctors

For patients with more than one chronic illness, a coordinated health plan and a coordinated health team are key to positive outcomes. As a person with pulmonary arterial hypertension and congenital heart disease, I deal with the delicate balancing act of coordinating different medical teams continuously. This past spring, I had the privilege of interviewing congenital heart disease specialist, Dr. Alison Meadows, about coordinating care among specialists.

As the director of the Adult Congenital Heart Program for Northern California Kaiser Permanente, she deals with a variety of congenital heart patients every day, many of whom are living with multiple chronic diseases such as PH, liver disease, etc. Here she answers some of my questions about how to figure out just who's responsible for what.

What can I do to facilitate communication among my specialists between appointments?

It is very important for patients who have chronic diseases to have their doctors communicate with each other. More importantly, it is very important for the patient to facilitate this if it is not already happening. If your doctors are not communicating and sharing information, ask them to do so. Make sure that all the doctors have all the records from your tests, follow-up letters, second-opinion letters and notes from the doctors who are part of your care. Be sure that you are active in your care and medical decisionmaking.

What should I do if two of my doctors disagree about a course of treatment?

It is important to find out why they disagree. Some disagreements are simply differences in style; some are based on provider experience. Often there are no right or wrong answers. Importantly, the patient must be comfortable with the ultimate decision. Patients should seek a second opinion if they are not sure how to proceed. If the doctor is not comfortable with this, then that doctor is probably not the right provider for them. Patients have to go with the doctors that they trust.

When I get a cold, a fever, or other "red flag" symptoms, whom should I call and in what order?

In many cases, your primary care provider (PCP) is a good doctor to make decisions about your care and help decide whether or not you should call one of your



Dr. Alison Meadows



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specialists. If you are clearly having a symptom that is related to one of your chronic illnesses, call the appropriate specialist directly.

I have so many doctors! Do I really need a primary care physician on top of all my specialists?

Yes. The main purpose of a PCP is coordination of care and prevention. This doctor's job is to stay on top of "the rest of you" and do routine screening. They will keep you on track to get your colonoscopy, mammogram, lipid panel, etc. Seeing your PCP is a preventive measure to keep the rest of your body healthy. Patients with chronic diseases need to remember that they, too, are aging. General health issues will affect them as well. People with chronic diseases are now living longer and are acquiring the "normal" types of diseases and conditions that come with aging. The PCP can also deal with other issues that can affect the patients' health and well-being such as stress, anxiety and depression.

I have a different specialist to treat each of the diseases that I'm living with. But isn't it possible my diseases are interacting? Whom do I ask about this?

Yes, all organ systems interact. This is why you need to have coordinated medical care. You need to continually challenge your providers to look at you as a whole person. This is also why it's important for you to have one central coordinator and decision-maker. This person can be a specialist or your PCP. Whoever this person is has to be willing and interested in taking the lead. ♦

By Melinda Schissel, PH Patient

To share your strategies for coordinating care among specialists, join PH Plus, PHA's email group for patients with associated diseases. Visit www.PHAssociation.org/EmailGroups#PHPlus