PATIENTS WITH multiple diagnoses, multiple specialists and medications prescribed by different providers can find managing their healthcare overwhelming. Idealistically, patients’ primary care physicians (PCPs) would play “quarterback” for them, but this rarely happens in the real world. PCPs are very busy with full patient loads, electronic medical records to maintain and insurance paperwork to manage. And, while they don’t have the time to know every aspect of their complex patients’ diagnoses and care, the good ones will let these patients be partners in their care.

Unfortunately, doctors often don’t consult each other about their patients’ care. Most often, this is because they want to respect each other’s expertise and authority. If patients have specialists whose areas of expertise overlap, such as immunology, ENT or pulmonology, problems could present if these specialists’ views differ about how patients should be treated.

Understanding these issues, patients can use some strategies and tools to better help manage their medical team.

Managing the PCP Relationship

Many PCPs are limiting visits to discussing one or two issues for insurance billing reasons. As such, complex patients might benefit from making appointments every three months to six
months (in addition to their regular wellness exam) to bring their PCP up to date on medical issues, specialists they have seen, what specialists have recommended, etc. Those appointments are also a good time to review medications and side effects, how well the medical team is working and whether any new specialists would be beneficial. Good PCPs will also check on how patients are holding up under the stress of dealing with complex and chronic health issues and offer suggestions for stress management.

**Medical Summary**

Patients can create a medical summary, which should be updated often, to carry with them to all appointments. Helpful things to include in the summary are current doctors and their specialties and phone numbers, pharmacy contact info, major diagnoses and dates of diagnosis, allergies, daily medications with dosages, as-needed medications, and past surgeries and procedures. The first sheet should summarize as much information as possible; subsequent sheets can offer more detail, if needed.

An easy way to create a medical summary is to sign up for an annual subscription service such as MedicAlert. These types of services provide step-by-step templates for in-case-of-emergency (ICE) situations and full medical histories. Patients can order jewelry with an ID unique to them that will provide healthcare workers the toll-free number to call to get the information needed to care for them during a medical emergency.

Once a medical summary is created, patients can simply write “see attached” on new patient forms and attach a copy of it. This saves patients from having to repeat their story over and over again. It also ensures they don’t leave anything out when meeting new specialists.

**Building the Team**

There are many ways for patients to find specialists for their medical team. Patients can look for university-based providers, HMOs with integrated care models such as Kaiser, or community-based providers in private practice or affiliated with non-university hospitals. Referrals can come from patients’ PCPs, local patient support groups, other trusted specialists, family and friends, or local doctor ratings guides. Sometimes it is a good idea to check with multiple sources and find specialists who are repeatedly recommended.

University-based healthcare providers are often involved in research studies and may know the very latest information about treating patients’ conditions. They are also apt to have electronic medical records that are integrated across departments, facilitating communication between specialists. However, university hospitals can have long waits for services and be difficult to get into for urgent care.

Integrated HMO models can also simplify care coordination for patients without long waits that can be found in university-based health systems. The downside is that, normally, patients can be treated only by in-network specialists. The exception to this is if there is no in-network physician of a particular specialty; in that case, special authorizations need to be obtained to go out-of-network.

Community-based providers are often easier to get in to be seen than university-based caregivers. They may also keep more “sick appointments” open for their patients’ urgent healthcare needs. The care patients receive may feel more intimate, but the doctors may not know as much about the latest treatments available for patients’ care. Also, patients will likely have to do much more of their own care coordination.

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Regardless of the site of care, it is a good idea for patients to ask new specialists if they are willing to take on their care given their complex medical histories. Not all specialists want to work with patients with complex medical conditions, so it’s better to find this out right away and look for a better match than to waste time on a specialist who isn’t going to want to work with a patient. It is also a good idea for patients to ask a specialist exactly what role they want to play in their care.

**Negotiate Specialists’ Boundaries**

Sometimes, when specialists’ areas of expertise overlap, it may become necessary for patients to decide which specialist they want to take care of each aspect of their health. For instance, an ENT may treat sinus infections, while an immunologist treats all other infections. Patients may actually need to negotiate this
with their specialists so everyone knows where they fit into the patients’ care team. If the specialists agree, great! If they don’t, patients may need their PCPs’ help in creating a different set of boundaries that will work for the specialists. Or, they may have to find new specialists.

Running List for Specialists
A paper notebook or electronic journal can be used for making a separate running list for each specialist. Patients can use this to jot down questions and information they want to communicate whenever something pops into their heads. Sometimes specialists convey information to each other through patients rather than calling each other. For instance, if one specialist wants another to run a test or consider a new medication or dose, they may ask patients to discuss this with the other specialist the next time they see them. The running list is a great way to keep track of these types of requests.

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Symptom Tracker
Patients can create a symptom tracker to track basic vitals, any major symptoms doctors want reported, days bedridden, sleep habits, antibiotic usage, etc. An easy way to build this is in Excel with dates across the top and symptoms down the side. A simple “x” when symptoms are experienced may be sufficient, or patients can use a pain scale or record any other information in the grid that will be helpful to them and their doctors.

Tracking symptoms over time in a consolidated tool can show important trends in patients’ health, and it can help doctors optimize their patients’ treatment plans. This information can also be used for ongoing disability paperwork.

Managing All Those Meds
When complex patients are treated by multiple specialists, there is an increased risk of adverse medication interactions. For patients with a large number of daily and as-needed medications, it can be very helpful to fill all of their prescriptions at a single pharmacy, avoiding mail order if at all possible. Using a single pharmacy improves the odds that potentially dangerous drug interactions are found before any harm is done.

Pill sorters can also be helpful — one by the sink for morning and night pills, and one to carry for daytime pills. Patients can pick a day of the week to fill the pill sorters, which allows them to see if they need to order any prescription refills for the following week. This will ensure they never run out of necessary medications. It is also advisable for patients to travel with at least a few extra days of pills in case there are delays.

Managing Medical Records
The length of time for which doctors and medical facilities are required to retain patients’ medical records varies by state. Typically, it ranges from seven to 10 years. However, for certain diagnoses, it can be critical to have records for hospitalizations, surgeries, complete diagnostic testing, etc., for patients’ entire lives. This is especially true for conditions such as primary immunodeficiencies or neurological conditions for which treatments alter future test results, and only cessation of treatment would “prove” patients are still ill.

Patients who have a need to keep decades of old records can create paper or electronic files, one for each diagnosis, and update them with new records as needed. These packets of information can then easily be copied when patients are meeting a new specialist, need to provide proof of disability, or need the specific records related to a diagnosis for any other purpose.

Say Thank You Often
Treating patients with complex medical conditions is very rewarding for some specialists because they know they are making a difference in their patients’ lives. A verbal heartfelt thanks in an email or a card on “doctor appreciation day” are all appreciated by providers brave enough to take on the challenges of helping patients with complex and chronic medical conditions.

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