

Facing the Perils of Medical Care

By
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Even for those without special needs, medical care is a mixed blessing. The system is not user friendly. If you have Multiple Chemical Sensitivity, there are myriad exposures. It is absolutely crucial that you be prepared and proactively involved in all stages of your care. Here are suggestions on how to do that.

PCP

You may want to have a primary care physician (PCP). This allows you to get tests and prescriptions and have someone who knows you if you break a bone or have some other emergency. A PCP can also refer you to specialists such as a cardiologist (heart), neurologist (brain), physical therapist, etc.

You can have a family doctor, internist, Nurse Practitioner, Physician's Assistant, or even a specialist as a PCP. You might ask others for recommendations for a PCP. However you will need one who meets your needs and who takes your insurance. If you are "dual eligible" (have both Medicare and AHCCCS/Medicaid) you'll need a PCP who takes both Medicare (or your Medicare Advantage Plan) and your AHCCCS plan. There are sliding scale clinics (you pay less if low income) and discounts for cash.

It is helpful to find a PCP who knows Multiple Chemical Sensitivity (MCS) is a real illness. You may need to call your insurance company to change PCPs so your appointment is covered. Sometimes a doctor who is not accepting new patients can be talked into it. You can call the day before your appointment if you want to ask them to not wear fragrance, use hand sanitizer, etc. It may or may not happen. Use the word "allergic." It can be difficult to get accurate information about their pesticide schedule. If they spray once a month and the date varies, it might be safer to make an appointment two weeks after they spray to avoid being sprayed.

Your First Appointment

At your first appointment you will be "establishing care," choosing that doctor as your PCP. The first person you see will be the front desk. If you have someone to go into the front desk for you, it is helpful as you can wait outside. Waiting rooms are generally fragrant. They will want your insurance cards and photo ID (driver's license, etc.). There will be a lot of papers to fill out. If you call and get some of these (like medical history) mailed to you ahead, off gas them, and fill them out in advance, it will save a lot of hassle and exposures. If you have a lot of diagnoses you can type them up and attach them to the papers. Have a second copy for the Medical Assistant or nurse. You can do the same with allergies. They will want to know your reactions. The papers will ask what pharmacy you use. You may need to do advance research to find one that has the brands you tolerate (if you tolerate certain brands of generics), takes your insurance (if any) and is cooperative re: which meds have dye, etc. Small locally owned pharmacies may be more helpful but more costly

The second person you will see at your appointment is the Medical Assistant (MA) or nurse. They will take your vital signs: blood pressure, pulse, temperature, oxygen level and your weight. You may want to keep track of this information over time so you know your normal in order to detect any future abnormal. Be nice to this person. They are your link to scripts, referrals, etc. Get their name and direct phone line if possible. Send a thank you when they have been helpful.

Next they ask why you are there. If you are “establishing care,” they will want your diagnoses, allergies, medications and supplements. If these are extensive, having a copy of each to hand them can be helpful for all concerned. You usually get to ask for three things per appointment. These might be a) establish care, b) get lab orders (to test thyroid, vitamin D, etc) c) get prescriptions (including oxygen). It is important to take in a copy of your most recent lab work if you are asking for a related prescription (like thyroid). Don’t spend a lot of effort explaining things to the MA/nurse. Save your energy for the doctor. The MA/nurse just puts the three things in the computer.

The third person you will see is the PCP. By now you may be fatigued and brain fogged. It’s good to write out everything you want to discuss in advance on paper and if someone comes with you to your appointment give them a copy. Keep track of what you’ve covered by crossing it out and make notes of the doctor’s responses. Some people audio record the appointment. DO NOT assume the info you gave the MA/nurse got to the doctor. You might write at the bottom of your paper what you hope to walk away with (test order, script, referral). Ask how they want to be contacted between appointments (fax, phone, or email) for refills and so forth.

You can be more in depth in explaining things to the PCP but they are busy and appointments are not lengthy. So be realistic about what can be covered and bring up the most urgent first. Some PCPs are willing to just call you with lab results. Some insist on discussing results in person. You can mention how difficult it is for you to come in due to travel and “allergies,” but they will only do so much to accommodate you. If you are discussing a particular problem (like neck issues) you might give them related data (like X-rays or previous doctor reports).

Once you have been back to your PCP a few times you might get them to sign a letter such as requesting an opt out from a smart meter. This requires taking the letter in typed on a letterhead with their name, address, phone, and fax so all they have to do is sign it. You could also take it on a snap drive in case they want to modify it. This is only a reasonable request once they know you and they may or may not do it.

Specialists

If you choose to go to a specialist it is prudent to ask others who is good. You don’t have to settle for the one suggested by the referral department or PCP. You can request a particular specialist, but make sure in advance that they accept your insurance. You may have to get a referral. Call the specialist’s office to make sure they have the referral before you go. Take a copy of the referral and any test/documents that led you to this specialist. There will be more paperwork and the process will be similar to the PCP. PCPs are used to doing what specialists

suggest, so it can be helpful to have an “environmental doctor” as a specialist. Although this could be an AAEM (American Academy of Environmental Medicine) doctor, it could also be an MCS-literate internist, NMD (naturopath) or other medical practitioner. This allows you to have your environmental doctor ask your PCP for tests they may not be familiar with (like the Shoemaker tests) or get scripts they may not be familiar with (like oral nystatin). It also helps you to avoid things like an MRI if you have Electrical Hypersensitivity (EHS). If you have an NMD, your PCP might be willing to prescribe at their suggestion so it’ll be covered by a Part D Drug plan “because they don’t take Medicare.”

Tests

Doctors, especially specialists, like to do tests. You need to decide in advance what you’re willing to do. Lab work is usually less harmful than some things. You may want to take benzalkonium chloride packets if you react to isopropyl alcohol fumes and request that they put the constriction band (usually fragrant) over your clothes, not skin. You may have to fast, so be sure to find out in advance. If you do fast, bring food, meds, and the supplements you normally take after your first meal. Some labs take appointments online which will save **lots** of waiting time.

If you have EHS, you will have to decide what you can survive and how important is the information to be obtained. MRIs are very high in magnetic field. More than one person believes they first developed EHS after an MRI. Nuclear medicine has less magnetic field but lots of high frequency (HF) radiation. Some people with EHS tolerate one or two X-rays but do worse with more, or if they are at head level. Some people can tolerate ultrasounds but not CTs or CTs but not contrast ones or one contrast agent but not another. If you do badly with an anesthesia, test or contrast agent, keep track of what you reacted to (add it to allergies). You may have to ask what was used. Tests can change; they may have new procedures or contrast agents. Only you can assess the risk versus benefit. What works for one may not for another. An environmentally aware doctor can alert you to unknown hazards like triclosan on sutures. Anesthesia is often a problem for people with MCS. Independent specialty clinics may be more receptive to your special needs for a simple procedure like a colonoscopy.

Medical Records

No one will keep track of you as well as you can. Doctors usually look at recent lab work and notice if it is “in range.” Not trends over time (except with cancer). You can get copies of your lab work by signing up online for the patient portal of your doctor or by signing up online through the lab company (Lab Corp, etc.). If you are not online, you can sign something when they draw your blood and they’ll mail you the results. One person’s white blood count was dropping for ten years before anyone noticed and would do anything. She was identified with a rare bacterial infection because she kept track of her lab work and asked questions. Save all your lab work so you know *your* normal.

You can get reports of visits with your PCP or specialists from the Medical Records department. This is usually a separate department of the clinic or hospital. You'll have to get paperwork and sign it and return it. Reports can be interesting. "He wears glasses." (You don't). It can help you determine whether you want to go back to that doctor and, if so, you can ask questions like what does "terminated secondary to fatigue" mean. You can also correct inaccurate information (medications, diagnoses, etc.).

It is wise to save the patient information from the pharmacy on any medications you take – despite the inconvenience of offgassing them. This information can help you determine if you are having a symptom or a side effect of a medication.

Emergency

It is good to be prepared for an emergency. One option is wearing a medic alert bracelet saying "allergies - see wallet card" and putting relevant info in wallet. You might put your emergency contact on the wallet card or bracelet too.

You can go to Urgent Care for some things (shingles) but need E.R. for others (heart attack). Having a list of allergies, diagnoses and medications with you at all times is wise. Doctors may listen better to other doctors than patients with special needs, so it is smart to have with you something in writing from a doctor about needing to avoid pesticides, remodeling, fragrance and cleaning chemicals. Heal Tucson (healsoaz.org 520-297-7992 PO Box 36404, Tucson AZ 85740-6404) has a helpful Medical Packet available by mail or online. Ann McCampbell MD (annmccampbell.com) has online documents also.

If you are allergic to a local anesthesia (like lidocaine) or the preservatives/epinephrine in it, you may want to get a preservative-free anesthesia from a compounding pharmacy and keep it with you. Benadryl swabbed on skin can numb an area for minor incisions. You may need less anesthesia (possibly ¼) than others and request less.

Diagnoses

It's good to have a list of your diagnoses, including who diagnosed the condition and when. If you are diagnosed with something new, you have the right to choose whether to follow the standard medical protocol for that illness.

If they suggest medications, you can take the prescription but research the medicine and talk to others regarding it prior to deciding whether to take the medication. MayoClinic.org has great articles on medications. Supplement Your Prescription by Hyla Cass discusses nutrient deficiencies created by medications and what supplements to take with particular medications (like CO Q 10 for statin cholesterol lowering meds). Make sure to read the side effects on the patient information from the pharmacy in order to distinguish illness symptoms from side effects.

If they want to do non-emergency surgery, you can talk to others who've had it. You can find out the best surgeon and request him/her. You can make your needs known regarding anesthesia, although unfortunately updated protocols frequently no longer use what worked for you previously.

If they want to do chemo or radiation, you can choose to do them or make radical dietary changes (vegan, macrobiotic) or pursue spiritual and/or holistic alternatives. These are serious decisions that only you can make. The Cancer Fighting Kitchen by Rebecca Katz lists foods and spices for surviving chemo and fighting cancer. Just realize you do have choices, including not doing anything.

Reading Medicare Summary Notice

If you are on Medicare, you will eventually get a notice of coverage of medical tests and appointments, Urgent Care visits, etc. (what has been paid). This is often received long after the appointment and can be surreal. Tests (like an ultrasound) will have one fee for the procedure and another for the doctor's interpretation, possibly on separate statements. There may be other fees for a procedure such as hospital, anesthesia, etc. You have 120 days from when you receive the notice to protest things that are not covered. There will be a date printed by which they must receive your protest. If something is not covered due to wrong diagnostic code ("The information provided does not support the need for this service or item"), it might be worth asking your doctor to submit another diagnostic code. Medicare pays 80% of covered services (some things, like the A-1-C blood test for diabetes are not covered.). If you have secondary insurance, hopefully it will pay the other portion.

If you have a Medicare Advantage Plan, whether HMO or PPO, check to see how to protest non-coverage and the deadline for doing so. It is prudent to check ahead regarding what will be covered.

Other Possible Benefits From Some Medicaid Plans

There may be a service that will pick up medications at the pharmacy and bring them to you. You need to pay the pharmacy ahead by credit card on the phone. They will also pick you up and drive you to appointments, but people with MCS are unlikely to tolerate the driver or their vehicle due to fragrance and cleaning products. They will also pay for a hotel if indicated for a procedure and you live at a distance. *They* book the room, so you'd have to contact the motel directly re: special needs. You can also fill out a Travel Reimbursement Form to have a friend be reimbursed for gas to drive you to an appointment in their car. You also need a signed letter from the practitioner stating you were seen on that date (sometimes called work/school status or release). Call your plan. You may get different answers from people who answer the phone, so you may need to call again if you are not helped. Lastly, if you have both Medicare and Medicaid (dual eligible) you may be allowed to change your Part D drug plan mid-year, not just in Fall.

Doctors, tests, medications, and hospitals can cause a lot of harm, but may be helpful, even lifesaving. Only you can assess the cost benefit. It is essential to be highly involved in your care before, during, and after medical visits and as prepared as possible.