



Tips for Communicating with your Healthcare Providers (HCPs) – Pearls and Pitfalls

Created by a Patient / HCP

1. You are the expert on you. Share that expertise with your HCPs in a confident and respectful way. It can be intimidating to explain your situation to an HCP, but HCPs can be intimidated too, especially when a patient is a zebra and has a long, complicated medical situation.
2. You are in a tandem-driver's seat with your HCPs. It truly is a partnership, so do not be afraid to advocate for yourself. Ask your questions. Share your concerns. And be open to possibility.
3. In general, leave Dr. Google at home. Make the most of your appointment and ask the HCP everything you ask Dr. Google – and be prepared to listen for answers, not just to prove them wrong. If you want to discuss something you found on the web, print it out and bring it with you to reference. If you are hearing things that are inconsistent with things you have learned from a trusted source or are aware of a new treatment approach, ask your HCP about it in a non-threatening way.
4. Online support groups can be an amazing resource to learn about other's experiences and may give you information about resources and options, especially in the rare disease arena, but they are not meant to provide medical advice. If you have questions about a patient's experience you read about, ask your doctor about it to get their perspective.
5. Understand that there are ways that HCPs are trained to think about most likely/most common and work towards less likely/less common. This takes several steps and takes time.
6. Do not walk in demanding an "eyes to thighs" MRI/PET/CT, etc. The pace of your care/workup is often dictated by your insurance. Specific reasons/diagnoses/findings are required to justify advanced imaging. Sometimes results have to be confirmed many times before advanced imaging is approved. Ask about the overall plan: first-second-next steps. If needed, enlist your HCP to help in preparing an appeal to an insurance company
7. When providers think about ordering tests/studies, they also think about what will need to be done with the results and what the results can mean. For example, "I will order plasma metanephrines. If it's positive, then is it POSITIVE or is something interfering with the results? If negative, is it really negative? What other testing should be done to confirm these results? What conditions could cause these results?" This process also takes time.
8. Your journey to diagnosis has likely been long, scary, and frustrating, which can often lead to depression and anxiety. Taking care of your mental well-being is very important. Consider seeing a therapist as part of your treatment.

Special thanks to dedicated volunteers for creating this resource. The Pheo Para Alliance is a 501c3 organization whose mission is to empower patients with pheochromocytoma or paraganglioma, their families and medical professionals through advocacy, education and a global community of support, while helping to advance research that accelerates treatments and cures.

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9. Most HCPs are not intentionally looking to be uncaring. Some may feel unprepared when confronted with Zebras. If you are feeling uncomfortable with the care you're receiving, ask for a referral to another provider who may be more experienced with Zebras. It can be hard to ask for this, but you matter and you should feel comfortable with your provider(s). Similarly, you should overcome any discomfort you may feel in asking for a second opinion if you feel that is needed. You can also reach out to info@pheopara.org to find a pheo para center in your area.
10. When discussing symptoms, focus on the most commonly associated symptoms of pheo para. Other symptoms you are experiencing may be the result of the illness, but long laundry lists of complaints tend to numb providers' ears. Begin discussion of symptoms with the most important symptoms; don't wait until the end of the appointment to mention your more serious conditions.
11. Take a pen and notebook to your visit. What do you want to address? Turn your cell phone OFF. Be engaged, take notes as your provider is talking. A checklist will help you and provider stay on track.
12. Be prepared and come to your appointment with a list of your questions and concerns, your medical history, medications that you are taking, results of previous lab tests, a symptom diary, family medical history, etc. If possible, have someone accompany you to be a second "set of ears" and to take notes.
13. Make sure to get a copy of your appointment notes, test results and imaging, and clinic notes. Check them for accuracy and keep them for your records. Accurate appointment notes can be critical in determining short-term/long-term disability and help other physicians understand your history. Make sure to tell a loved one where you keep your medical binder in case of an emergency.
14. Keep a running list of questions and concerns for your HCP on your phone/device as they pop up.
15. If you are satisfied with your care, express that to your provider. This goes a long way when forming relationships.

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