

LET'S TALK:

Questions & Conversations You Should Have with Your Health Care Provider



If you are a patient that has recently been diagnosed with a rare disorder or chronic condition, you may be experiencing feelings of anxiety or uncertainty as you begin to navigate your new diagnosis.¹ You may also be feeling inundated by new information and health terms that accompany your diagnosis.²

While this may feel like a challenging time, there are ways you can become more familiar with your diagnosis and become a stronger self-advocate in your long-term care management.³ A part of managing your condition, is building an effective relationship and care plan with your provider. However, if you have not previously had to visit a health care provider or specialist often, or do not have much experience engaging with the health care system more generally, this may seem daunting and cause you to feel like you don't even know where to start or the questions to ask.⁴

At Aimerd Alliance, we understand this journey can feel complicated and confusing. With that in mind, we have developed the below prompts and questions to help patients and caregivers have productive conversations with their providers and health care staff.

BEFORE THE VISIT



RECORD YOUR SYMPTOMS

You are the expert on how your body feels and the symptoms you're experiencing. Therefore, it is important for you to keep a record of your symptoms to help healthcare practitioners efficiently diagnose and treat your conditions. For a starting point, try writing down how long you have had these symptoms, how often they occur, when they occur, where they occur, what improves or worsens them, and any other details you think may be relevant.

Having this record enables you to provide an accurate and detailed account of your symptoms the next time you see your health care provider. The more details you can describe during your appointment, the more information your health care provider can use to determine the cause of your symptoms and the best plan for treatment.



BE YOUR OWN HEALTH ADVOCATE

If you haven't been to your health care provider in a while, it can be easy to get swept up in paperwork, medical history, and meeting with your provider. With all this going on, it can be easy to forget to ask a question you had or ask for clarification about what your health care provider is telling you.

Therefore, to prepare for an upcoming appointment, you should write down any concerns regarding your symptoms, costs, and anything else that may be relevant to you continuing to seek treatment. It may also be helpful to draft specific questions you would like to ask or include some goals you have for the appointment.

Lastly, if you are scheduling an appointment with a new health care provider, take some time to think about what characteristics you are looking for in a provider. Does gender matter? Are you looking for someone from the same cultural background? There are no wrong answers. Identifying a healthcare provider you are comfortable with is important to ensuring you are able to be candid about your health with your provider.



WRITE DOWN YOUR MEDICAL HISTORY (SURGERIES, MAJOR ILLNESSES, PROCEDURES)

Having an accessible written record of your medical history can make complex medical forms less daunting. Often, the first thing you experience when entering a health care office is insurance and medical history forms. Medical history forms may ask information about your medical history, including previous surgeries, major illnesses, and procedures. Actively drafting your medical history prior to arrival can help ensure you include a complete medical history on the form.



WRITE DOWN YOUR FAMILY'S HEALTH HISTORY (DISEASES OR MAJOR MEDICAL EVENTS)

Creating a record of your family's medical history ahead of time can help reduce stress and ensure that all of your family members' relevant medical histories are included. Your family's health history can include a list of diseases or major medical events that affected biological relatives on both your maternal and paternal sides of the family, including grandparents, parents, siblings, aunts, uncles, and your own children. Many health conditions can have a genetic component, which means it can be passed down from parent to child. Therefore, knowing your family health history can help identify conditions that may be passed down within a family.

However, if you do not have access to your family's health history, don't worry, your health care provider will still be able to help!



MAKE A LIST OF ALL THE DRUGS & SUPPLEMENTS THAT YOU TAKE

It is important for health care providers to know all the medicines you take to ensure your provider can account for any potential drug interactions. If you have a hard time remembering the medications you take, you can prepare a list of all the medications (over the counter and prescription), supplements, and vitamins you take and how often you take them. It is also important to note the reason for taking the medication, dosage, and how long you have been taking the medication.



MAKE A LIST OF ALL YOUR HEALTH CARE PROVIDERS & PREVIOUS APPOINTMENTS

If you see multiple health care providers, it's important to tell them about each other, as this allows your providers to offer a cohesive, coordinated plan of care. To help ensure your providers are in contact with each other, you can make a list of all your health care providers, their contact information, reason for visits, date of last visits, and the results of visits (the diagnosis, if any test were conducted, and whether follow up was needed).



UNDERSTAND IMPORTANT FINANCIAL INFORMATION

Knowing the cost of a health care visit ahead of time can help reduce financial stressors and uncertainties. All group health plans and health insurance companies are required to provide insured individuals with a "summary of benefits and coverage" (SBC). An SBC describes the benefits and coverage under your plan.⁵ You can refer to the SBC or call your insurance company to determine the plan's coverage. Specifically, under the SBC, you should be able to review the cost of visiting a health care provider's office. You should also determine whether the provider is in-network (if applicable) by asking your provider, calling the insurance company or visiting the insurance company's website. You can also call your provider's office to ask what, if any, information the office needs about your insurance policy before the appointment. Lastly, you can always ask the provider the estimated cost of the visit and if needed, whether there are any financial assistance programs or payment plans available.



DURING THE VISIT

If you haven't been to your health care provider recently, it can seem like there is a lot of information to review. Below are some helpful tips to ensure you feel your voice is heard and concerns are addressed during the appointment.



TAKE NOTES DURING THE APPOINTMENT

Taking notes on your conversations with health care staff and practitioners can help you get the most out of your appointments. During appointments, you can take notes on anything you feel is necessary, including information on testing, diagnosis, treatment options, follow-up care, medications, next steps, and any other important information. Taking notes can help reduce anxiety, prompt important questions, and increase your understanding of the diagnosis treatment plan.

If you like to use a notebook to take notes, remember to bring one with you to the appointment. However, if you forget, you can always use your phone or ask the office staff to borrow a pen and piece of paper!



QUESTIONS TO ASK REGARDING THE DIAGNOSIS:

If you are visiting a health care provider to receive a diagnosis, below are some helpful questions you can ask to ensure you understand the diagnostic process:

Is testing required?

Some conditions may require testing before a diagnosis can be made. Diagnostic testing may include blood tests, organ function tests, screening tests, and imaging tests. You should make sure you understand the types of tests available and what the health care provider is looking for on the test. If you are unfamiliar with the tests, just ask your doctor to explain it!

Is testing typically covered by insurance?

Understanding the costs associated with care can help reduce financial uncertainties. If your health care provider is requesting a type of test, you can ask what the cost of the testing would be and if the testing is generally covered by insurance. You can also refer to your health policy's SBC or call your insurance company to assess the plan's coverage.

What does the diagnosis mean?

If/when you receive a diagnosis, you should make sure you understand it. There are no wrong questions. For example, questions you may want to ask could include how serious is the diagnosis? What does it mean for my day-to-day, short-term, and long-term? If you are unfamiliar with any medical terms, be sure to ask the doctor to explain them.



What caused the condition?

If you have been recently diagnosed it is common to want to understand how you developed this condition. It can also be an important question to understand if you have biological children that it could be potentially passed down to. Determining whether it is caused by genetic modifiers, lifestyle choices, environmental risks, or a combination of these factors, may guide the course of treatment.

What risk factors are associated with this disease or condition?

Some chronic diseases and rare conditions are associated with other risks factors. Knowing the risks associated with a particular disease or condition can help you avoid future health problems by making informed decisions regarding treatment and other factors that may influence your health, including, lifestyle, diet, and environmental factors.



QUESTIONS TO ASK REGARDING TREATMENT:

What are the current treatments options?

Understanding your treatment options is important to ensure you and your provider select a treatment that matches your lifestyle. Therefore, make sure to tell your health care provider about personal circumstances that may impact your ability to follow a treatment plan, such as, lack of transportation, cost, need for childcare to receive treatments, etc. If no treatments are currently available for your condition, you can ask if there are any clinical trials available or if there will be a treatment available in the future.

What are the instructions for taking the treatment?

If you are prescribed a medication for treatment, make sure you ask how frequently you need to take the medication and for how long to take it? You can also ask about potential side effects associated with the medication and if you can consume other substances while taking them. (e.g., alcohol or other drugs).

How will I know the treatment is effective?

It is important that you know what to look for to assess whether the treatment plan is effective for your condition or disease. Specifically, you should know when symptoms should resolve and what to do if your symptoms don't resolve within an expected timeline.

What are common side-effects?

When assessing treatment options, you should consider common side-effects associated with treatments. Some treatments may be associated with short-term side effects, like nausea or drowsiness, while others may have long-term side effects, like heart damage or fertility problems.

What is the cost of treatment?

Understanding the costs associated with a particular treatments, can help you and your provider identify a treatment that is affordable for you. To determine if a particularly treatment is affordable, you should ask if the treatment is generally covered by insurance, if there is a financial assistance program available, or if there are lower cost treatments that can be tried first. You can also refer to you health insurer's SBC or call your insurance company to assess the plan's coverage. Lastly, many pharmaceutical companies offer financial assistance to cover the cost of copays. Ask your pharmacist or visit the drug manufacturer's website to determine if copay assistance is available.



Are there consequences if I delay treatment?

For various reasons, some individual may consider delaying treatment. For many chronic diseases and rare conditions, delays in treatment may cause serious and irreversible disease progression. If you are considering delaying treatment, tell your provider why, to ensure you understand the risks associated with delay. If you are concerned about starting or continuing treatment, you should speak with your provider to determine what steps can be taken to ensure access to treatment.



QUESTIONS TO ASK REGARDING FOLLOW-UP CARE:

Do I need to see a specialist?

Chronic and rare conditions can often require specialty care. Specialists have additional expertise in specific branches of medicine, conditions or types of treatments. A practitioner may refer a you to a specialist if they've made a diagnosis that requires specialized care, or to help determine a diagnosis or determine the best treatment plan.

Do I need follow-up care?

Some conditions may require you to follow-up with your practitioner. Follow-up care can help your health care provider ensure your treatment is effective and make further assessments and adjustments if necessary.

If my symptoms don't improve, worsen, or return, when should I come back?

If your condition does not require you to return for a scheduled visit, it can be helpful to know when to book a follow-up visit if the treatment plan is not successful. If your provider has limited availability,

it can be helpful to book an appointment for the date symptoms are expected to be improved by and cancel it if symptoms resolve. Be sure to check with your health care provider's office cancellation policies to avoid a cancellation fee.

Are there any symptoms I should watch for?

Watching for certain symptoms may be an important part of managing a chronic disease or rare condition, which may make you more likely to develop other conditions. Knowing which symptoms to monitor can help you proactively manage and prevent the development of additional conditions.

How might lifestyle changes, nutrition, or other environmental factors help or harm my condition?

Even if not the root cause of a condition or disease, changes in lifestyle, nutrition and environmental factors may protect you from disease progression or improve associated symptoms. Conversely, these factors may also cause the disease or condition to progress. Therefore, you should be aware of how these lifestyle, nutrition and environmental factors affect your condition.

If treatments aren't working, are there clinical trial options?

If treatment plans are not working or stop working, you can ask your health care provider if there are any clinical trials that you may be eligible for. A clinical trial is a research study that tests a new treatment in individuals with a certain condition or with certain characteristics to prove whether the treatment is safe, effective, and can provide a benefit not otherwise available with current treatments.⁶



AFTER THE VISIT



KEEP TRACK OF YOUR SYMPTOMS AND HOW YOU FEEL ON YOUR MEDICATION

Following the start of a new treatment plan, you should monitor how you feel and how your symptoms respond to a new medication. It is important to closely monitor the effect a medication has so you and your providers can ensure you are on the best course of treatment. Keeping a detailed account of how the prescribed treatment is impacting your condition enables you to provide an accurate and detailed account of the treatment, making it easier for a provider to assess whether the treatment is still appropriate and effective.



KEEP TRACK OF YOUR ADHERENCE TO THE TREATMENT PLAN

Following your treatment plan diligently and avoiding skipping dosages is important to determining if a treatment is effective. Therefore, you should take note if you are unable to take your medication consistently and why this is occurring. For example, do you need to set an alarm, need transportation help getting to the office for an infusion, or need financial assistance to afford your cost-sharing for the medication?



IF YOU HAVE CONCERNS, COMMUNICATE WITH YOUR PRACTITIONER

BUT IF YOU ARE FEELING UNHEARD, SEEK A NEW PRACTITIONER

If something feels wrong, contact your health care provider, or 911 in an emergency. Additionally, if you have questions you did not get to address during your appointment you can always call your provider and see if they are available to speak with you on the phone, or schedule a follow-up appointment, if necessary. If after speaking with your health care provider, you are still concerned and feel that your concerns were not being heard or addressed, don't hesitate to get a second opinion.



BE YOUR OWN ADVOCATE & BECOME AN EXPERT IN YOUR CONDITION

Following diagnosis, take the time to research your condition so you can take the best care for yourself. Learning more about the condition may also help you be a stronger advocate with your health care provider on your next visit. However, when conducting research, ensure you are reviewing credible information from legitimate sources, such as medical journals or other vetted sources. Patients and caregivers may also find support groups beneficial for anyone impacted by chronic illness or rare disease.



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