

AASPIRE

# Healthcare Toolkit

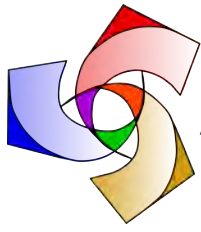
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## Healthcare

Step-by-step navigation of the primary healthcare system, including finding a provider, making an appointment, preparing for a visit, having a visit, and following up on care.

### **Contents**

- Finding Providers
- Making Appointments
- Preparing for a Visit
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# Healthcare Toolkit

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## Healthcare: Finding Providers

### **Contents**

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- How do I find names of healthcare providers?
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# Healthcare: Finding Providers

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Last Updated September 29, 2015

## 1 What is this topic about?

This section is about how to find a healthcare provider, like a doctor, nurse practitioner, or physician's assistant. If you don't already have a healthcare provider, or if you want to change healthcare providers, this section gives some ideas about how to find a new one. It may not be possible to follow these suggestions in a step-by-step fashion. You may need to go through the steps more than once, or in a different order, before you find a healthcare provider you like. Not all steps or suggestions in this section may apply to you.

## 2 How do I find names of healthcare providers?

### 2.1 Option 1: Get referrals from people or organizations you know and trust.

For example, you could ask:

- **Friends, family, or co-workers** - Ask people you trust if they have a doctor they like. Someone you know might be able to give you first-hand information about what a healthcare provider and his or her office and staff are like.

- **Other professionals** - If you go to other healthcare professionals, or if you use a disability service or social service agency, ask them for recommendations.
- **Autism Groups or Communities** - If you are involved with a local autism group or community, either online or offline, you can ask there. These communities might be able suggest providers with experience working with people on the spectrum.
- **Hospitals** - Hospitals may have local physician referral services. Contact your local hospital and ask if it has a physician referral line or someone at its facility who can give physician referrals. Different hospitals may have different words for the people who offer this service. Often they are called referral specialists or health advocates. Ask if the hospital has a physician referral service that you can contact.

*You can ask, "I'm looking for a healthcare provider. Do you have a physician referral service, health advocate, or someone who can help me find a provider?"*

**2.2 Option 2: If you have health insurance, get lists of providers covered by your plan.**

Health insurance companies have lists of healthcare providers for you to choose from. These lists can usually be found on a web site, by calling the company on the telephone, or in a booklet sent to you by the company. People with public insurance can contact their state's [primary care office](#) to help find possible providers.

*To get a list, you can ask, "I'm looking for a healthcare provider. Do you have a list of providers I can choose from?"*

### 2.3 Option 3: What to do if you don't have health insurance.

You don't have to have health insurance to see a doctor. It may require some research to find what options are available in your area. Try asking about or searching for "free clinics," "low-cost clinics," "safety net clinics," "providers that accept self-pay patients," and "clinics that use a sliding scale." Some ways to search for these options are:

- Information and referral services such as [211](#).
- Search the Internet.
- Ask at your local hospital.
- If you go to other healthcare professionals, or if you use any disability or social service agencies, ask them for recommendations.
- Contact your state's [primary care office](#) to help find possible providers.

You can ask, "Do you have any information about free, low-cost, safety net, self-pay, or sliding scale clinics?"

### 2.4 Option 4: Online Internet searches

- **Regular Internet searching (e.g., Google)** - Search for 'family practice' or 'general internal medicine' (or whatever specialty you are looking for) and any other keywords that will help you narrow the search. For example, you may want to include the city or county where you live, or the name of a clinic that is convenient to you.
- **Licensing Boards and Professional Organizations** - If your state has a medical licensing board (most do) they may also offer provider lists or searches on the Internet or telephone. Doctors often belong to professional organizations that may offer information and doctor referrals on

their websites. The American Medical Association has a list of both [national](#) and [state](#) medical licensing organizations.

- **Medline Plus** has an extensive directory to help in locating health professionals, services and facilities.
- **Web Mapping Services** - Many of the popular search engines like Yahoo, Google or Bing offer mapping services. You can use these to locate providers in your area.

## 2.5 Option 5: Off-line searches

Searches for clinics or providers can be done offline through

- Yellow Pages listings or other directory listings.
- Contacting licensing boards, the American Medical Association, or other professional organizations on the telephone or in person.
- Traveling around your neighborhood and looking for clinics.

If you find a clinic or provider convenient to you, contact them or stop by their front desk and ask if they are accepting new patients at their practice.

*If you're interested in a particular clinic, you can ask, "I'm interested in becoming a patient at your clinic. Are any healthcare providers at your clinic accepting new patients?"*

*If you're interested in a particular provider, you can ask, "I'm interested in establishing care with (provider's name). Is (provider's name) accepting new patients?"*

### 3 How do I know if I can go to a healthcare provider or clinic?

The answers to these questions could change whether you are able to see a particular healthcare provider or not, so it's best to find out the answers before you schedule an appointment. If you find you can't go to a particular provider or clinic, you may have to find another provider or clinic to try.

#### 3.1 If you have insurance, find out:

- Does the healthcare provider or clinic accept your insurance?

Ask, *"Do you take (insurance company name)?"*

- If yes, is the healthcare provider in-network or out-of-network? An in-network provider is someone who has agreed to see on that company's insurance plan at a reduced cost. The amount you have to pay to see an in-network provider is usually less than the amount you have to pay if you see an out-of-network provider. The insurance company may pay less or not pay anything for services you receive from an out-of-network provider.

Ask, *"Is (provider's name) in-network?"*

- If out-of-network, find out what your insurance will pay or not pay. Can you afford that? Is it worth it to still see this provider instead of a provider in your network? You will likely have to get this information from your insurance company, not the provider's office.

Ask, *"How much will be covered if I see an out-of-network provider?"*

- Not all insurance plans cover all treatments. If you need a certain kind of care or treatment, try to find out if your insurance will cover that.

### 3.2 If you don't have insurance, find out:

- Does the healthcare provider or clinic see patients who don't have insurance (self-pay)?

Ask, *"Do you see uninsured, self-pay patients?"*

- Is there a sliding scale or other low-cost option?

Ask, *"Do you have a sliding scale or other low-cost option for self-pay patients?"*

- Can you afford to pay what the provider or clinic is asking?

Ask, *"How much would it cost for me to see (provider's name)?"*

### 3.3 Important questions for everyone are:

- Is the healthcare provider taking new patients?

Ask, *"Is (provider's name) taking new patients?"*

- Do you have transportation to get to this healthcare provider or clinic?

This may be something you just find out on your own, or you could also ask the provider or clinic, *"What is the best way to get to your office (in a car, on a bus, walking from a location, etc.—whatever fits your situation)?"* or *"Can you help me arrange transportation to your office?"*

- Does the healthcare provider or clinic have office hours that work with your schedule?

This may be something you just find out on your own or you can ask, *"What are your office hours?"* or *"Does (provider's name) have office hours during (time that works with your schedule)?"*



- How long will it be before you can get a new patient appointment? If the appointment will be too far out to meet your needs, you might want to consider looking for a healthcare provider who can see you sooner.

*Ask, "Will (provider's name) be able to see me before (date you need to see them by)?" or "How long would it take to get an appointment with (provider's name)?"*

## **4 How do I know if a healthcare provider is a good choice?**

### **4.1 Do research or ask questions in advance.**

You can learn some things about a provider or clinic before your appointment by:

- Looking up the provider or clinic on the Internet.
- Asking people you know for their opinions about the provider or clinic.
- Contacting the office staff and ask them questions.

Some questions you might want answered are listed in the next section Questions to Consider. You might not be able to answer all these questions before your appointment.

### **4.2 Questions to Consider**

These questions can be good to consider when making a decision about whether to see or continue seeing a healthcare provider. Some questions may not be important to you. That's OK; you can just ignore them. You may not be able to answer many of these questions until you have had one or more visits with the provider.

- Do the healthcare provider and office staff have the right credentials and training?
- Do they have an accessible way for you to communicate with them (example: secure messaging system, alternatives to telephone)?
- Do they have knowledge of autism or experience with people on the autism spectrum?
- Do they have knowledge or experience with your medical problems (if your medical problems are uncommon)?
- Do they have attitudes you agree with about autism or disability?
- Do they have communication skills and style that work well with yours?
- Are they willing and able to make the accommodations you need?
- Do they respect your right to self-determination?
- Are they interested in including you in your care?
- Do you like their approach to medicine?
- Do they have the resources in their office or clinic that you need or want? Examples: care manager, social worker, "medical home", secure messaging, on-site lab/pharmacy.

Tip: Doctors in the United States are licensed in the state where they practice. Check your state's website to find out what office deals with medical licenses. Many have a place where you can search for a doctor's license by name. They should also be able to tell you if any complaints have been filed against that doctor. If you don't have access to the Internet, try your state's Information and Referral Line (such as [211](#)) or look in the state section of your phone book for an office that handles medical licenses.

### **4.3 Think about how things are going after the first few visits.**

After you've seen the provider one, two, or three times, ask yourself the "Questions to Consider" again. Sometimes it takes a while to learn if a provider will meet your needs.

## **5 What if a provider turns out to be a bad fit for me?**

If this isn't a good fit, it's OK to switch to another provider. (But, sometimes relationships take time and no relationship is perfect.)

## **6 Should I disclose my ASD diagnosis to my healthcare provider?**

Whether to tell your provider about your ASD diagnosis is your choice. In most cases, the benefits of disclosing a diagnosis far outweigh the risks, but you need to weigh the risks and benefits for yourself to know what is right for you. In general, telling your provider may help them better understand you and make working with you easier (but some providers may also need some education). For more information on the possible benefits and risks of disclosure, see the section in Your Rights in Healthcare on Disclosure.

## **7 Summary**

**Finding A Provider** - Healthcare providers can be found by:

- Asking people or organizations you know and trust (for example, friends and family, other professionals, autism groups, or hospitals).

- Through listings provided by your health insurance provider (if you have insurance).
- Searching for safety-net or self-pay clinics (if you do not have insurance).
- Searching on the Internet, including using links provided by licensing boards and professional medical organizations.
- Searching off-line, including through Yellow Pages, contacting professional organizations off-line, or looking physically for a convenient provider or clinic in your neighborhood.

**Knowing If You Can See a Provider** - Make sure:

- The provider takes your insurance (if you have insurance) and that you can pay for the in-network or out-of-network service.
- The provider takes self-pay patients (if you don't have insurance) and that you can pay for the service.
- The provider is taking new patients.
- That you can get to the provider when you need to.

**Knowing If the Provider Is a Good Choice** - Some ways to figure out if a provider is a good fit for you are:

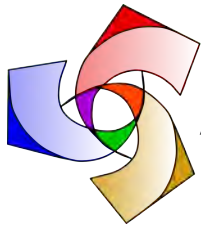
- Find out information about the provider by looking them up on the Internet, asking people you trust for their opinions, and contacting the provider's office.
- Schedule a "getting to know you" visit with the new provider.
- See the provider a few more times, and think about how the visits went.
- Use the list of "Questions to Consider" as a guide to some things that might be important to think about in figuring out if a healthcare provider is a good match for you.

**What to Do If the Provider Was a Bad Choice** - If after a few visits you don't feel comfortable with a particular healthcare provider, it's absolutely OK to see a different provider.

**Disclosure** - It's your choice if you want to tell your new healthcare provider about autism. Telling your provider may help them better understand you and make working with you easier (but some providers may also need some education about autism).

## 8 Links and Resources

- [Your Healthcare Information Guide](#) - This site contains a whole host of resources, guides and links to a variety of healthcare topics written in plain language. It was created by a husband and wife team who are currently working in healthcare fields.
- [Get Affordable Healthcare](#) - Health Resources and Services Administration (HRSA) is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable. Their website has a list of resources for the uninsured as well as a search engine that can be used to search for community or safety-net clinics by geographic area.
- [211](#) - State Information and Referral system for help with food, housing, employment, health care, counseling and more.



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## Healthcare: Making Appointments

### **Contents**

- What is this topic about?
- What might I want to know before I schedule an appointment?
- What might I want to know after I schedule an appointment?
- I can't use the telephone or have trouble with scheduling, what should I do?
- What might I say making an appointment?
- Summary

# Healthcare: Making Appointments

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Last Updated September 29, 2015

## **1 What is this topic about?**

This topic is about how to make an appointment with a healthcare provider. Different providers may have slightly different ways to make appointments. This section gives some basic information about appointments that should be similar for most providers.

## **2 What might I want to know before I schedule an appointment?**

Before you or your supporter contacts the office, you might want to have the following information ready.

1. The contact information for the provider's office (telephone number, address, etc.)
2. The reason why you are making the appointment (for example, new patient visit, sore throat, annual exam, etc.).
3. Your (or your supporter's) contact information in case the office needs to call you back.
4. What days and times you are free.

5. Who to call for a reminder, and that person's phone number.
6. If you have health insurance, who your insurance provider is.
7. Any other questions that you may have about the appointment.

You might not need to know all of these things, depending on the particulars of the appointment.

The [Making an Appointment Worksheet](#) has places to organize all of this information.

### **3 What might I want to know after I schedule an appointment?**

By the end of making the appointment, you may have learned some of the following things.

- The date and time of your appointment.
- Where your appointment is located.
- The name of the healthcare provider you will be seeing.
- Anything special you need to bring to the appointment, or do before the appointment (for example, not eat any food eight hours before).
- The answers to any other questions you had about the appointment.

You might not need to know all of these things, depending on the particulars of the appointment. The [Making an Appointment Worksheet](#) has places to organize all of this information



## **4 I can't use the telephone or have trouble with scheduling, what should I do?**

Unfortunately, many providers or their offices do not feel comfortable using non-secured text-based ways to make appointments, such as email or text. Here are some ideas if you have difficulty with the telephone:

- Find out if your healthcare provider has an electronic messaging system (for example, MyChart) and use that system for scheduling.
- Ask someone you trust to make the appointment for you.
- Go to the office in person and make the appointment face-to-face.
- Use an online relay or caption service such as [AT&T Relay Service](#), which will allow you to type and/or read.
- Have someone contact the office, or go to the office in person, and make special arrangements.

If you have a hard time with scheduling things, here are some ideas that may help:

- Ask the healthcare provider's staff or front desk people to help you with scheduling.
- Ask someone you trust to help you with scheduling.
- Use calendar software on your computer or mobile device to keep track of appointments.
- Use the [Making an Appointment Worksheet](#) which organizes all of the steps for scheduling and gives a sample script you can use.

## 5 What might I say when making an appointment?

What you say when making the appointment will be a little different depending on the type of appointment you need. Here is a script for how to start the conversation in a few different situations. Each fill-in-the-blank script is followed by an example. When making the appointment, you would put your own information in the blanks, not read the example.

- Establish Care or New Patient visit

*"Hi, my name is (your name) and I would like to make a new patient appointment with Doctor (the provider's last name) to establish care."*

Example: Hello, my name is Jane Smith and I would like to make a new patient appointment with Doctor Connors to establish care.

- Follow-up visit

*"Hi, my name is (your name) and Doctor (your provider's last name) wanted me to schedule a follow-up visit (time frame)."*

Example: Hi, my name is Edward Smith and Doctor Jones wanted me to schedule a follow-up visit within the next four weeks.

- Other types of visits

*"Hi, my name is (your name) and I am a patient of Doctor (your provider's last name). I am calling to schedule an appointment with my doctor because (describe the reason for the visit)."*

Example: Hi, my name is Jane Smith and I am a patient of Doctor Connors. I am calling to schedule an appointment with my doctor because I went hiking last week and I came back with a rash and it's not getting better.

The conversation will be a little different each time after this point. The person you are talking to might ask you some questions, or you might want to give

information right away like saying when you are available. A script for other things to say is included with the [Making an Appointment Worksheet](#).

## 6 Summary

Before you make an appointment you may want to know:

- Your provider's contact information,
- The reason for the visit,
- Your contact information and the telephone number for the reminder call,
- When you are free to see the doctor,
- Your health insurance information.

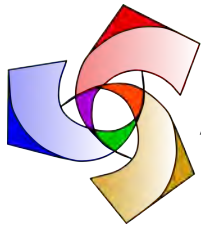
After you make the appointment, you may want to know

- Date, time, and location of the appointment,
- Name of the healthcare provider you'll be seeing,
- Anything special you need to bring to or do for the appointment.

If you have trouble with the telephone some alternatives might be

- Use electronic messaging, if available,
- Have someone help you,
- Make the appointment in person,
- Use a relay service.

To start making an appointment, say *"Hello, my name is (your name) and I'm calling to make a (type of appointment) appointment with (provider's name). The reason I am making the appointment is (reason)."* A more detailed script can be found in the [Making an Appointment Worksheet](#).



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## Healthcare: Preparing for a Visit

### Contents

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- What might I do to prepare for my visit?
- What might my provider want to know about my symptoms?
- What will my provider need to know about my medications?
- What might I need to know about paperwork?
- What might I bring to a visit with my healthcare provider?
- What extra things might I need to bring if it's my first visit, or I haven't seen my provider in a long time?
- How might I prepare for the office and the waiting room?
- I have a hard time with the waiting room, what might I do?
- I have trouble with transportation to the office, what might I do?
- Summary and Tips

# Healthcare: Preparing for a Visit

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Last Updated September 29, 2015

## **1 What is this topic about?**

This topic is about things you might do to get ready for a visit with your healthcare provider. It includes tips and checklists for knowing what to bring to a visit, how to handle the office and waiting, and how to prepare for interacting with your provider. You do not need to do all of these things to have a healthcare visit.

## **2 What might I do to prepare for my visit?**

### **2.1 Take Care of Paperwork Before the Visit**

You might be asked to fill out an intake form before the visit. Many clinics and offices are willing to mail intake forms before the visit. You can ask about this when you make the appointment, or any time up to a week before the visit. If this will be your first visit to a new healthcare provider, or if you haven't seen your healthcare provider in two or more years, there might be more paperwork to prepare. See the section on "What do I need to know about paperwork?" for more information.

## **2.2 Make a List of Topics to Cover**

It's not always possible to cover all the things you want to in one visit with your provider. To cover everything, especially if you haven't been to a healthcare provider in a long time, more than one appointment might be needed. Here are some tips for how to make sure the most important things get covered.

1. Make a list of all of the things you would like to cover with your healthcare provider. It's OK if you put more things on the list than you can cover in one visit.
2. After the list is finished, take a look at it and decide which of the things on it are the most important. Here are some questions you can ask yourself that might help in figuring out which things on the list are the most important:
  - "If we are only able to go over two of the things on this list, which two do I want them to be?"
  - "Which of the things on this list are giving me the most discomfort?"
  - "Which of the things on this list am I most worried about?"

If you aren't sure which things are the most important to cover in the visit, you might find it helpful to talk it over with someone you trust.

3. When you see your healthcare provider, show them the whole list at the start of the appointment and tell them that you don't expect to do everything in one visit. Let them know which of the things on the list are the most important to you. Be prepared to talk about the list a little with your provider and decide together on an "agenda" for the visit. Also be prepared that your provider may have a different suggestion for what's most important on the list to cover during that visit.

## **2.3 Prepare for Tests or Procedures**

- You may have been asked to prepare ahead of time for a certain test or procedure. Your healthcare provider may ask you to not eat anything for a

certain amount of time before the visit (called fasting), take—or not take—certain medications, or follow some other special instructions. Check with your healthcare provider 48 hours before the visit to make sure you are prepared.

- If you are very worried about a test or procedure, contact the office staff and ask if it is possible to come see any equipment first, or to do a “trial run” of the procedure before doing it for real. This may not always be possible but has been helpful for some. An alternative is to ask for a detailed description of the test or procedure.

## 2.4 Practice with Role-Playing

Some people may find it helpful to role-play the visit with a supporter or friend to help prepare for a visit. Let your partner know what your health concern is, then have them pretend to be the doctor. Practice explaining your issue to them. Have them ask you questions in response. Here’s a short example:

*Doctor: Hi. So the nurse says you are having problems with your ear?*

*Patient: Yes.*

*Doctor: Oh. I’m sorry to hear that. Which ear is it?*

*Patient: The right one.*

*Doctor: Just the right one?*

*Patient: Yes.*

*Doctor: Does it hurt?*

*Patient: Yes.*

*Doctor: How much?*

*Patient: I’m not sure how to describe it. A lot?*

*Doctor: That’s OK. How often do you notice it?*

*Patient: All the time.*

*Doctor: Do you have trouble hearing out of that ear?*

*Patient: Yes. I also can’t sleep on that ear because it hurts.*

Practice until you feel comfortable that you can describe the problem clearly. It's OK to stop and talk about anything you don't understand or get suggestions or clarifications from your partner. There is information about what healthcare providers usually want to know about symptoms in the section "What might my provider want to know about my symptoms?"

### 3 What might my provider want to know about my symptoms?

Your provider will likely want a full description of your symptoms to understand what is causing them and how to treat them. When providers ask about symptoms, there is specific information they usually want to know. That information is listed here. Thinking about this information in advance may help you prepare for a discussion with your provider.

If you have more than one symptom, you may need to think about these things for each symptom, or you can group them together if you think they are part of the same problem (for example, a cough, runny nose, and sneezing that all started at the same time). Do whatever works best for you. Not all items apply to all symptoms. You do NOT have to have answers to each item. If you don't have answers, something doesn't apply, or you don't know the answer, that is OK.

**What is the Symptom (or set of symptoms)?** Examples of symptoms—conditions that you can see or feel—are: pain in a part of your body, tingling, itching, burning, shortness of breath, a cough, diarrhea, fevers, chills, a rash, trouble sleeping, and feeling sad or anxious.

*Example: belly pain*

**Location** - Your provider may want to know what part of your body is affected. For example, where does it hurt? Is it your arm? Your abdomen (or belly)? If so, what part of your abdomen? Or where is the rash? Where is the tingling or itching?



*Example: right side of belly below ribs*

**Severity** - How bad is it? How much does it hurt? Does this bother you a little bit or a lot? Often the nurse or doctor will ask you to give a number value to the pain. Usually they use a scale of 1 to 10 where 1 is very little pain, 10 is the most pain you can imagine, and 5 is a pain that is midway between least and most pain you can imagine.

*Example: it hurts really bad when it's happening, but doesn't hurt at all when it's not happening*

**Quality** - If the symptom is pain, what is the pain like? Is it sharp, dull, stabbing, cramping, burning, throbbing? How would you describe it?

*Example: crampy*

**Duration** - How long has it been going on? When did you first notice the symptom? In some cases, you may be able to pinpoint an exact date or time. In other cases, it is OK to give a general idea - for example has it been going on for hours, days, weeks, months, or years? About how many? Sometimes it helps to think about other events in your life. Example: "My birthday is in July. I remember it started around the time of my birthday."

*Example: started about three months ago*

**Onset** - What were you doing when it first started? For example, did it start while you were exercising or at rest? Did you fall or hurt yourself? Were you in an accident? Did you just wake up with the problem?

*Example: it just started happening; I wasn't doing anything special*

**Frequency or Patterns** - Does the symptom come and go or is it there all the time? About how often does it happen? Have you noticed any patterns?

Does it happen at a certain time of day, week, month, or year? What brings it on? Have you figured out any ways that you can predict when it will happen or how bad it will be? About how long does it last each time?

*Example: It happens right after I eat on most days. It lasts 30 to 60 minutes when it happens.*

**Change From Baseline** - What is normal for you? How is this problem different from how you usually feel?

*Example: I've had heartburn for years, but this feels different from heartburn. It's in a different place and is more crampy feeling.*

**What Makes it Better / Worse** - What kinds of things make it feel better? What makes it worse? For example, does it get better or worse when you are lying down? Does it change depending on what you eat? Do certain positions or activities make it better or worse?

*Example: eating fatty foods makes it worse, eating slowly seems to help*

**Related Symptoms** - Do you get other symptoms at the same time? For example, when some people get chest pain, they also feel short of breath or dizzy or sweaty. Or when some people get a headache, they also feel nauseated and have blurred vision.

*Example: nausea, but only sometimes*

**Other People** - Do other people around you have the same symptoms? For example, do other people you work with or live with have similar symptoms? Is this something that runs in your family? Do other people who interact with you have a similar condition?

*Example: I don't know anybody else with similar symptoms.*

**Effect on Lifestyle or Activities** - How has it affected your life? Does the symptom keep you from doing things that you normally do? Does it make it hard to exercise, work, go out, sleep, eat, or read?

*Example: It makes it hard for me to eat or for me to leave the house.*

**Treatments** - What have you tried doing to treat your symptoms so far? Has it helped? What happened when you tried the treatment?

*Example: I've tried Tums and Zantac, but they didn't help at all.*

**Why Now?** If this problem has been going on for a long time, what made you come in to see your healthcare provider now? Has anything changed? Have you noticed that you have had a change in your weight?

*Example: It's been getting worse and worse. It used to be just sometimes, but now it's after almost every meal.*

**Your Thoughts** - What do you think is causing the problem? What do you think is going on? Are you worried about something in particular, like that it might be due to a cancer or heart disease?

*Example: I'm worried about stomach cancer.*

On the [Symptom Worksheet](#) these items are listed with blanks that you can fill in to help prepare information about your symptoms.

## 4 What will my provider need to know about my medications?

Healthcare providers need to know about any medication you are taking, including over the counter medications like aspirin, vitamin, or nutritional supplements. Below is a list of the information providers usually want to know. It's OK if you don't know the information on this list. You can just put your medicine bottles, tubes of ointment, or other medication containers in a bag and bring them with you when you see your healthcare provider. If your healthcare provider wants to know any information about the medications, he or she can then look at the container.

**Medication name** - The brand or generic name of the medication.

**Strength** - Some medications have different strengths. The strength is usually listed in a unit of measurement like grams or milligrams. For example, the strength might be 2 grams or 100 milligrams. If your medicine bottle lists two strengths, tell your provider both strengths.

**Dose** - The dosage of the medication you take. For example, two pills, half a cup, or one tablet. If your medicine bottle lists two dosages, tell your provider both dosages.

**Times Per Day or Per Week** - How often do you take this medication, and when? For example, someone might take one pill in the morning and one pill after dinner.

**How much medication you have left** - Do you have a lot of the medication left or are you completely out of that medication?

## 5 What might I need to know about paperwork?

If you are making a new patient visit, or if you have not seen your healthcare provider in two or more years, you might need to prepare some paperwork. It's best to prepare this paperwork as far before the appointment as possible.

## 5.1 Patient Intake Forms

Patient intake forms are where you fill out your basic personal and medical information before a visit. Most providers require that all their patients fill these out. Your answers on the forms will help providers know the most important things about your health quickly without having to read through all of your medical records. Ask the office staff to mail you a copy of the forms before your visit. You also have the option to fill out the forms in person before the visit, though this could be stressful. These forms are not usually very accessible. You may want to ask someone to help you with the forms. It is also OK not to fill out everything on the forms. You can leave parts blank if you don't understand them, or aren't sure if they apply to you. Your healthcare provider will ask you for more details during the appointment if he or she wants them. To fill out the forms, answer the questions or fill in the blanks. It is OK to use another piece of paper if you need to. The most important parts of the form are:

- Any major procedures you have had (for example, surgeries)
- Any major illnesses you have had (for example, cancer, or something you had to go into the hospital for)
- Any chronic conditions you currently have (for example, diabetes, allergies, any conditions you're taking medication for)
- Any medications you are currently taking

If you already have a summary of your past health issues that you or someone else has made for you, you may be able to use that to help with the forms. Some people need to ask others to help with their past history information. For example, parents may help you remember important health events from when you were much younger.

## **5.2 Medical Records**

Your medical records are all of the paperwork and electronic records from all of the providers you have seen in your life, including for hospitalizations or emergency department visits. If you are seeing a new healthcare provider for the first time, he or she will want copies of your medical records to learn in depth about your healthcare history and needs. Most healthcare providers have a form they use to automatically transfer medical records from one provider to another. Because your medical records are private, you typically need to give your written permission before the records can be transferred. Ask your new provider's staff ahead of time if they have a form you can send to your previous provider so your records can be transferred. Note: Records transfers can take up to 30, days so it's best to ask for your records to be transferred well before your first visit. If your records can't be transferred in time for your visit, bring the name, address and phone number of any healthcare providers you have seen in the past.

## **5.3 Medical Information Release Forms**

Your health information is private. It typically can not be shared with people who are not healthcare providers without your permission. Medical information release forms let you give your permission for people who aren't healthcare providers to know about your medical information. If there are people in your life who will be closely involved in your healthcare (examples: husband or wife, parent, support staff), you'll need to fill out a medical release form. This form lets the clinic or healthcare provider share information about your medical care with that person. You only need to fill out these forms if you want someone other than your healthcare providers to know your medical information. If you want your healthcare provider to be able to share your medical information with another person, ask your provider's office for the forms to share your healthcare information with others. Most medical information release forms are pretty straightforward to fill out. They ask you to give the

name of the person you wish to have information shared with, check off what kinds of information the person can know, and then you need to sign them.

#### **5.4 Autism Healthcare Accommodations Letter**

This is a letter addressed to your healthcare provider which lists your customized accommodations information. Sometimes healthcare providers don't understand how to work with people on the autism spectrum. If you have any needs that have to be accommodated in order for you to get good healthcare, the letter may help providers to accommodate you. You can create your own customized Autism Healthcare Accommodations Letter on our web site using the Autism Healthcare Accommodations Report. The online tool for creating the letter works like a normal survey. After you fill out the survey, the tool will create the letter for your healthcare provider based on how you answered the survey.

### **6 What might I bring to a visit with my healthcare provider?**

Listed here are some things that can be helpful to bring with you to any visit with a healthcare provider. Not all things on the list might be useful to you. You can ignore the things that don't apply to your situation.

- Your health insurance card, if you have one. The provider's staff might ask you for your insurance card.
- Something fun to do in case you have to wait (examples: book, puzzle, fidgets, music player).
- Sensory items (examples: sunglasses, chewing gum, head phones).
- A list of questions or things you want to cover with your healthcare provider. More information about this is in "What might I do to prepare for my visit?"

- A completed symptom worksheet or information about your symptoms, if applicable. More information about this is in "What might my provider want to know about my symptoms?"
- Any logs or diaries you keep about your health problems (examples: blood sugar measurements if you have diabetes, blood pressure measurements if you have high blood pressure, symptom trackers if you use them).
- Containers (bottles, tubes, etc.) of all your current medications, or a list of all your current medications. If you bring a list, see "What will my provider need to know about my medications?" for what information they will need to know.
- Any instructions or paperwork you have been given by other healthcare providers since your last visit. For example, if you have been to the emergency room, have been hospitalized, or have seen any other healthcare providers since your last visit, you might have paperwork from those visits.
- Name, address, and any directions needed to get to the office.
- Anything your healthcare provider has specifically asked you to bring (if they have asked you to bring anything).

If this is your first visit with the healthcare provider, or if you would like to talk with your healthcare provider about your accommodation needs or strategies that may help make visits go more smoothly, also bring:

- A copy of your Autism Healthcare Accommodations letter for your healthcare provider (if you made one, see Autism Healthcare Accommodations Report)

There are some more things you might want to bring with you if this is your first visit or if you haven't been to see your healthcare provider for two or more years. They are listed in the next section "What extra things might I need to bring if it's my first visit, or I haven't seen my provider in a long time?" Here is [a checklist](#) you can use to organize what you might want to bring.



## **7 What extra things might I need to bring if it's my first visit, or I haven't seen my provider in a long time?**

If it's your first visit with a new provider, or if you have not seen your provider in a long time (for example, the last time you saw your provider was two or more years ago), you should try to bring everything listed in "What might I bring to a visit with my provider?", plus some extra things. The extra things are listed below. The paperwork parts are described in more detail in the section "What might I need to know about paperwork?"

- A short summary of your medical history (if you have one)
- Your old medical records, if you have them (This is described in more detail in the section "What might I need to know about paperwork?".)
- The names and addresses or fax numbers of your past healthcare providers, or of any other healthcare providers that you are still going to (your primary care provider and any specialists)
- Names and contact information of people who may be involved in your healthcare. Examples include the person they should contact in case of an emergency, your Healthcare Power of Attorney (the person who would make health-related decisions for you if you ever could not make them yourself), a guardian (if you have one), and anyone who helps you communicate between visits. If there aren't any other people involved in your healthcare, or you don't have some of these kinds of people, that's OK. You only need to bring their information if you have them.
- Your intake form, if you filled one out at home.

Here is [a checklist](#) you can use to organize what you might want to bring.

## 8 How might I prepare for the office and the waiting room?

Here are some things that may be helpful in preparing for the office and the waiting room.

- Have someone take pictures of the office and staff before your appointment. Many offices now have web sites so you may be able to find pictures of the staff there.
- Use Google Street View from [Google Maps](#) to view the outside of the facilities and see your route to them.
- Think about how you are getting to and from the office. Are you taking public transportation? Is someone picking you up? Is it a mix of both? You may want to print out directions for how to get to the office. You can also ask the office staff to provide you with a map or directions of how to get to their office. Make sure you have the proper fare, if it's required.
- Make sure you have any maps or directions you need. If the provider's office is in a large hospital or is confusing to navigate, you might want to ask for a map or directions. If maps and directions don't help, ask if someone at the office can meet you and show you where to go.
- Bring something to keep you occupied while you wait. Most providers who see adult patients don't keep games or toys in the office so make sure to bring whatever it is you like to do while you wait.
- Bring anything to help with sensory issues such as light (for example, sunglasses), sound (for example, headphones), or temperature (for example, a blanket or warm clothes). Remember it's OK to self-advocate, or have a supporter advocate for you if you need an accommodation. For example, ask the office staff to adjust the light, music, or temperature.

What else? The list above can get you started, but everyone is different. Think about anything else that might help you make it to the office and to feel more comfortable after you get there.

## **9 I have a hard time with the waiting room, what might I do?**

Here are some things your provider's office and staff can do that might be helpful. Please speak to (or have someone you trust speak to) the office staff to see if they can implement these if you think they will be helpful.

- Request to wait in the exam room or other private area.
- Request to wait in the car or other place outside the office building until it's time to go into the exam room. Make sure the office staff knows how to contact you when it's time for you to go in.
- Request that the office staff turn off the TV, radio, or other things that make noise in the waiting room.
- Request that the lights in the waiting area be dimmed or allow for natural light.
- Ask how long the wait is likely to be, or if there are unexpected delays.
- If you are unlikely to notice when your name is called for your appointment, make sure the office staff knows to come over to you or get your attention in another way.
- Have the office staff show you where the exam room is.

## **10 I have trouble with transportation to the office, what might I do?**

Your healthcare provider's office may be able to help you find local resources for transportation to your appointment. These resources might be special arrangements through your local transportation system (sometimes called para-transit), a volunteer driver program, or some other low-cost or free transportation service. Not all providers' offices have information about transportation. Here is some information about transportation that may be helpful.

- [Disability.gov](#) - The U.S. Government has a searchable list of transportation resources both nationally and by state.
- Community Transportation Association - This national advocacy organization focuses on transportation for individuals who do not have access to mass transit or private vehicles. It has a section on [medical transportation](#) as well as a section on [transportation for people with disabilities](#)
- [Project Action](#) - This is a national program for improving transportation for people with disabilities. It is administered by the National Easter Seal Society and funded by the Federal Transit Administration.

## 11 Summary and Tips

Some things you might want to do to prepare for a healthcare visit are:

- Take care of paperwork (intake forms, medical records transfer, medical release forms, accommodations letter)
- Make a list of topics to cover at the visit
- Prepare for any tests or procedures
- Practice for the visit with role-playing
- Work out what you want to say about your symptoms
- Put together information about your medications
- Make sure you have transportation and directions to the office
- Pack the things you might want for the waiting room and the visit

You may want to prepare information about your symptoms before the appointment. The things healthcare providers usually want to know about symptoms are:

- What is the symptom?
- Where is it happening?
- How bad is it?
- What does it feel like?
- When did you first notice it happening?
- What were you doing when you first noticed it?
- Are there any patterns to it?
- How is it different from what is normal for you?
- What makes it better or worse?
- Do you get any other symptoms at the same time?
- Do other people around you have similar symptoms?
- Has the symptom affected what you do?
- Have you tried to treat the symptom?
- What do you think might be causing the problem?

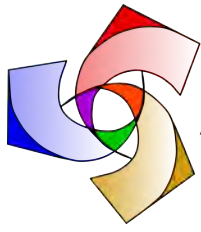
Some tips for coping with the waiting room are:

- Get familiar with the waiting room in advance, or have someone take pictures
- Ask to wait in a private room or somewhere else
- Ask office staff to turn off things that make noise or to change the lights in the waiting area
- Ask how long the wait is likely to be or to be told if there is an unexpected delay
- Make sure office staff knows how to get your attention

- Ask office staff to take you to the exam room when it is your turn

If you have trouble with transportation, ask the clinic or office if they have any transportation resources, or can help. You can also find transportation resources online, for example, at [Disability.gov](https://www.disability.gov). Checklists and worksheets:

- [Symptoms Worksheet](#)
- [What to Bring to a Visit checklist](#)



AASPIRE

# Healthcare Toolkit

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## Healthcare: During the Visit

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# Healthcare: During the Visit

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[www.aaspire.org](http://www.aaspire.org)

Last Updated September 29, 2015

## **1 What is this topic about?**

This topic is about things that might happen during a visit to a healthcare provider. It is also about ways to make the visit go more smoothly.

Although different things will happen at each visit, many visits follow similar steps. The steps are outlined in the section "What is likely to happen during the visit?". Each of the steps is then described in more detail in its own section.

This topic is about regular primary care visits. It is not about visits with specialists, emergency room visits, or other types of healthcare visits that will likely have different steps to them.

## **2 What is likely to happen during the visit?**

Below is a flow of the steps that often happen during a visit. These steps are not always the same. They may be different for each provider or they may change based on the reason why you are having the primary care visit. However, this is the flow of events that happens at most primary care visits.

1. Check in with the receptionist or front office desk when you arrive. The receptionist may ask you to sign in or wait to be checked in.
2. Wait to be called for your turn to see your healthcare provider.
3. Have the nurse or assistant take your vital signs and guide you to an examination room.
4. Wait for the healthcare provider to come into the examination room.
5. Have a conversation with your healthcare provider about your health and your concerns. Your healthcare provider may ask you some questions.
6. Get an examination by your healthcare provider. Sometimes, especially in teaching hospitals, your healthcare provider may also talk to their supervisor, or their supervisor may examine you or ask you more questions.
7. Have another conversation with your healthcare provider about what he or she thinks is going on with your health, and recommends as next steps. You may want to ask your healthcare provider some questions.
8. Work with the nurse or assistant if they come back after you've talked to your provider. The nurse or assistant may need to do some tests, give you a shot, give you some instructions, or do other wrap-up things.
9. Check out with the receptionist or front office desk before you leave.
10. Consider follow up instructions. You may have been asked to do some follow up things, like make an appointment with a specialist, get some labs or x-rays, fill a prescription, or do something at home. See the After the Visit topic for more information on follow up instructions.

### **3 What do I need to know about checking in when I arrive?**

It is best to arrive a little early for your visit so that you can check in. When you first enter the office, go to the receptionist or front desk and let the person there know you have arrived.

You can say, *My name is (your name) and I am here to see (your healthcare provider's name).*

If you have any paperwork prepared, give it to the person at the desk.

You can say, *"This is my paperwork. What would you like me to do with it?"*

The person behind the desk should let you know what to do next with the paperwork.

If you do not have any paperwork prepared—or even if you do—the person at the desk may give you more forms to fill out, or more papers to read. Most of these forms are part of standard care. Unfortunately, some can be very difficult to understand (for any patients). If you are worried about filling out or signing a form, you can ask the office staff, a nurse, or someone you trust to explain it to you.

After you are checked in, the person at the desk will probably ask you to wait until it is your turn to see your healthcare provider.

#### **4 What are some tips for handling the waiting room?**

Some tips for handling the waiting room are listed in the section, "I have a hard time with the waiting room, what might I do" in Preparing for a Visit.

If you think one of the tips might be helpful to you, bring it up to the person behind the desk at the end of the check-in process, and ask if the person can accommodate your needs. Explaining that you are on the autism spectrum can help the person see this as an accommodation and not just a preference. It can also be helpful to include briefly why it's important that you be accommodated, so the person knows you are not just being fussy.

Example #1:

*I am on the autism spectrum and I have a very hard time handling the waiting room. I worry it may stress me out too much to have a productive visit. Would you be able to text me on the phone when it is my turn, so I can wait outside where it's quieter?"*

Example #2:

*"I am on the autism spectrum and uncertainty can stress me out too much to have a productive visit. Would you be able to let me know right away if my wait will likely be longer than 15 minutes?"*

If you really don't wish to disclose your autism diagnosis, you can also be specific about the reason why you need to be accommodated without bringing up autism.

Example #3:

*"I have unusually sensitive hearing and sounds can stress me out too much to have a productive visit. Would it be possible for me to wait in a quieter area?"*

## **5 What might the nurse or assistant do before I've seen the provider?**

You will often see a nurse or assistant before you see your healthcare provider. This is normal in many clinics and offices. The nurse or assistant is an important part of the healthcare team. He or she communicates with your provider, and works together with your provider during your visit. The nurse or assistant has to keep your health information private just like your healthcare provider does. The nurse or assistant will usually show you to the examination room and get some basic health information from you. He or she may ask you the reason for your visit, about any medications you are taking, or for clarifications on some of your paperwork.

He or she will often take your vital signs. This may happen in the examination room or in another part of the office. For example, scales for measuring height and weight are sometimes in the hallway. Vital signs are:

- respiratory rate (how fast you are breathing)
- temperature
- blood pressure
- heart rate
- weight and height

The nurse or assistant will sometimes give you an examination gown to put on, and ask you to change into it. If you need the nurse or assistant to accommodate you with something, it is OK to ask. For example, you can ask him or her to give very specific instructions, or to guide you to the room instead of just pointing.

## **6 Tips for Staying Comfortable While Waiting for the Provider**

It is OK to ask the nurse or assistant for things that will help you feel more calm and comfortable while waiting for the provider to show up. For example, you can ask:

- how long it is likely to be before your healthcare provider shows up
- to be told if your healthcare provider will be delayed and your wait gets longer
- if you can wear your coat or other clothing over the examination gown until the provider comes in
- if the lights can be dimmed, shades opened, or other changes made to the light in the room

- if there is a quieter room available, or if you could wait somewhere quieter for your provider

It can be helpful to include briefly why it's important that you be accommodated, so the nurse or assistant knows you are not just being fussy.

You can say, *"I have a very hard time with (describe what makes you uncomfortable), and worry it may stress me out too much to have a productive visit. Would it be possible (describe the tip that you think will be helpful)."*

Example:

*"I have a very hard time with being cold, and worry it may stress me out too much to have a productive visit. Would it be possible for me to wear my sweater over my examination gown until the provider is ready for me?"*

## 7 What might my healthcare provider ask me?

If you have made a list of things you would like to have addressed, share it with your healthcare provider at the beginning of the visit so that you and your provider can set a plan for the rest of the visit. Then the provider will probably ask you questions regarding the issue(s) to be addressed at that visit.

Your provider will interview you about the symptoms of the problems you want to take care of. If you have used [a Symptoms Worksheet](#) to organize your symptoms, you might find it useful to refer to your worksheet when your provider asks you about your symptoms. Do not hand your provider the symptoms worksheet unless he or she asks you to see it. The worksheet is just for you to better be able to answer the provider's questions. If your provider is asking a lot of questions, it's not to be nosy or invade your privacy. Doctors

are trained to ask questions in a particular way in order to make a proper diagnosis and treatment plan. In addition to asking questions about your health concerns, many providers will ask you for information that may seem very personal. They do this because these things can have important effects on your health or healthcare. They do not do this because they think you are a bad person or the type of person who would do bad things. They ask these questions of everyone. It's best to be honest about this stuff. Personal or embarrassing questions might include:

- Habits - smoking, alcohol, drugs
- Diet and exercise
- Living situation, employment, disability status
- Intimate relationships - sexual preference, sexual activity, how many partners, birth control and STD control, threats, violence, abuse
- Mental health - depression, sadness, mania, anxiety, panic attacks
- Social supports, social life, stressors in your life
- Healthcare Power of Attorney, Guardianship, Emergency contacts
- Preventative health - see "Preventative Healthcare" section of "Staying Healthy".

## **8 I have a hard time answering these types of questions, what should I do?**

If you have trouble answering your healthcare provider's questions here are some things you can ask your provider to do that might make it easier for you to answer. Not all of these will be useful to every person. Not all of these will be possible. Providers are more likely to do these things if you pick the one or two most important suggestions for you.

- Specific Questions - Have your provider ask very specific, concrete questions and avoid very broad questions.
- Yes/No - Have your provider ask yes and no questions when possible.
- Extra Time - Ask the provider to give you extra time to respond to questions.
- Read written notes - Ask your provider to read notes you wrote before or during the visit.
- Examples - Have your provider give you examples of the types of things people may experience and have you explain if you experience them too.
- Multiple Choice - Ask your provider to give you a list of possible symptoms or answers to choose from.
- Life Events - Have the healthcare provider help with time questions by linking to important events in your life.
- Reword - Ask the provider to reword something if it confuses you.

It's OK to not know the answers to questions the provider is asking. It's also OK to not to be 100 percent exact or confident in your answers.

## **9 What might my healthcare provider do to examine me?**

The provider may need to examine your body to diagnose you and recommend next steps. The provider may examine you with his or her hands or with an instrument. The provider may touch or look in your eyes, ears, nose, mouth, breasts, spine/back, abdomen, extremities, genitals, rectum, or skin. What part of the body, and the kind of examination the doctor will do, depends on the health concern being addressed.

If your healthcare provider has a supervisor (for example, you go to a clinic in a teaching hospital), the supervisor may also examine you or ask you questions.



## 10 I have a hard time with being examined, what might I do?

If you have trouble tolerating exams or procedures, here are some things you can ask your provider to do that may make them more tolerable for you. Not all of these will be useful to every person. Not all of these will be possible. Providers are more likely to do these things if you pick the one or two most important suggestions for you.

- **Who Will Do What** - Have the provider explain what parts of the visit the nurse or assistant will do and what parts of the visit the doctor will do.
- **Explain First** - Have the provider explain what he or she is going to do before doing it.
- **Equipment** - Have the provider show you the equipment he or she will use before it is used.
- **Trial Run** - If possible, do a "trial run" of difficult exams or procedures before they are done for real. For example, practice with the equipment or walk through the steps that will happen.
- **How Long** - Ask the provider how long something is likely to take.
- **Warn** - Ask the provider to let you know when they are about to touch you or do something to you.
- **Clothes** - Ask if you can keep as many clothes on as possible or limit the amount of time you have to be undressed or in a gown.
- **Extra Time** - Ask for extra time to process things you need to see, hear, or feel before you have to respond (for example, pressing and asking if something hurts).
- **Avoid Touch** - Ask to be touched as little as possible during the exam.
- **Firm and Deep Touch** - Ask to be touched with a firm, deep pressure if possible (not a light touch).

- Sit or Lean - Ask if you can sit, lie down, or lean on something during procedures, when possible.
- Signals - Ask if you can use a signal to tell the provider that you need a break.
- Check In - Have the provider ask you from time to time if you are able to handle the pain or discomfort.
- Anesthesia - Ask if anesthesia is an option if you need it to tolerate a procedure.

## **11 What might I want to ask my healthcare provider?**

After your healthcare provider has examined you, they will talk about what they think is going on. You might want to ask your provider some questions about what they think is going on.

Here is a good list of questions you might want to ask your healthcare provider.

- What do you think is causing my problem?
- Is there more than one condition (disease) that could be causing my problem?
- What tests will you do to diagnose the problem and identify which of the possible conditions is present?
- How good are the tests for diagnosing the problem and the conditions?
- How safe are the tests?
- What is the likely course of this condition? What is the long-term outlook with and without treatment?
- What are my treatment options? How effective is each treatment option? What are the benefits versus risks of each treatment option?

- If my symptoms get worse, what should I do on my own? When should I contact you?

(Taken from article on [MedicineNet.com](https://www.medicinenet.com) by William Shiel, Jr, MD.)

## **12 What are some tips for understanding diagnoses and recommendations?**

Here are some suggestions that might help you make sure you understand your provider's recommendations. Not all of these will be useful to every person. Not all of these will be possible. Providers are more likely to do these things if you pick the one or two most important suggestions for you.

- Restate - Restate what the provider said in your own words to see if you got it right.
- Get Another Explanation - Ask a supporter who communicates well with you to re-explain the things to you.
- Write Things Down - Ask the provider to write things down, or write the things down yourself and have him or her check it.
- Get Names - Ask for the name of your health condition and look it up in a credible source.
- Discuss Options - If a decision about something needs to be made, discuss your options with a trusted person before making a decision.

## **13 I have trouble being included in decisions about my healthcare, what should I do?**

If you are having trouble being included in discussions or decisions about your healthcare, here are some suggestions as to how you can be more involved.

Not all of these will be useful to every person. Not all of these will be possible. Providers are more likely to do these things if you pick the one or two most important suggestions for you.

- **Extra Time** - Ask for extra time to make a decision. It's OK if that means you need to come back or communicate the decision at a later time.
- **Ask for Concrete Information** - Tell your provider to be very blunt and concrete with you about what will happen if you do or do not follow your provider's recommendations. If possible, have the provider give concrete examples.
- **Get Detailed Information** - Ask your provider to direct you to detailed information or resources about your health conditions.
- **Involve Others** - Have the provider give a person you trust detailed information about your health conditions and choices.
- **Discuss** - Discuss your healthcare choices with a person you trust and then speak to your provider about what you've decided.

#### **14 What might I do if there isn't time to cover everything I want to cover?**

Not all of your concerns can always be covered in one visit. If you're not able to get all of your concerns covered, it is OK to ask for another appointment to finish up. The front office staff or receptionist can usually help with scheduling another appointment.

#### **15 What do I need to know about preventive care?**

Preventive care includes things that can help prevent a major health problem, or can help catch a health problem when it is still minor or easier to treat. Pre-

ventive care includes things like cancer screening, vaccinations, and dental cleanings.

Some preventive care, such as screening for diseases like cancer or diabetes, needs to be done regularly. You may want to ask your healthcare provider during the visit if you need to make a separate preventive care appointment for anything.

For more information about preventive care, see the topic Preventive Care under Keeping Yourself Healthy.

## 16 More Tips for Communicating with Healthcare Providers

It is OK to ask your healthcare provider for things that will help you communicate with him or her better. Here are some tips to make it more likely that the provider will understand and give you what you need.

If you ask for accommodations, make it clear that something is a disability-related need, not a preference.

*Example: "Even though my speech is fluent, I have a really hard time communicating verbally. May I please write down my answers instead? It will help me give you better information."*

More information about asking for accommodations is found in "How do I request ADA accommodations for my healthcare?" in the Equal Access section.

- If someone helps support you with your healthcare, explain (or ask your supporters to explain) the role of your supporters to your healthcare provider. Different people have different ways they like to be supported. For example, some people like to do all the communication with their healthcare provider themselves and have the supporter just take notes, while others

may want the supporter to do most of the communication. Your healthcare providers may not understand what role you want your supporters to play in your healthcare unless they are told.

- It's OK to ask your healthcare provider to go more slowly. It's OK to ask your provider to re-explain something or write it down.
- Let your healthcare provider know that you respect how tight their schedule may be. One way to do that is bring a list of your health concerns and at the start of the visit discuss which of the issues to address right away, and which may need to be taken care of at another appointment. It is OK to ask for another appointment to get all of your concerns addressed.
- Show your appreciation for the provider's efforts. When the visit is nearing an end, you can simply say, "Thank you for your time and effort."
- Regular preventive care or follow-up visits may strengthen your relationship with your provider because you will see him or her more frequently.

## **17 What might the nurse or assistant do after I've seen the provider?**

The nurse or assistant might come back after you have seen your healthcare provider. He or she might talk to you about things the healthcare provider has recommended. For example he or she might go over any new medications, might show you how to do something you'll need to do at home, or might give you more information about your health condition. He or she might have instructions for you about testing, or about seeing another healthcare provider. The nurse or assistant might also do some tests or draw blood. Use the tips in the sections about I have a hard time answering these types of questions, what should I do?, What are some tips for understanding diagnoses and recommendations?, and More Tips for Communicating with Healthcare Providers for communicating with the nurse or assistant.

## 18 What about check out and follow up?

After you have seen your healthcare provider and done any other things with the nurse or assistant, you may need to go back to the front desk or receptionist and let them know you are done with your visit. Depending on your situation, there may be some extra steps to checking out. Examples of steps some people might need to take are:

- Schedule another visit with your healthcare provider to cover something that wasn't addressed at this visit
- Schedule a follow up appointment, lab, or other type of visit that the front desk or receptionist can help with (see the topic After the Visit for more details)
- Schedule a preventive care visit
- Pay for something

## 19 Summary

Most regular visits with a primary care provider follow these steps:

- Check in with the front desk
- Wait to be called for your turn with the healthcare provider
- Have the nurse or assistant take your vitals and show you to a room
- Wait for the healthcare provider
- Talk with the healthcare provider about your concerns
- Get an examination

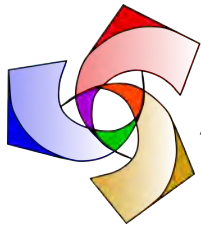
- Talk with the healthcare provider about what they think is going on with your health
- Work with the nurse or assistant on any final steps
- Check out
- Consider follow-up instructions

During all of these steps, it is OK to ask for things that can help you best participate in your healthcare. You may ask for things you need from front desk staff, nurses and assistants, and from the primary care provider. It is usually easier to get your needs met if you briefly explain why what you need really matters. Otherwise people might misunderstand and think it's just a preference or that you are being fussy.

Healthcare providers like to feel appreciated and respected, just like anyone else. It can improve communication with them to let them know you appreciate their work and respect their time.

If you aren't able to cover all of your health concerns in one visit, it is OK to make another visit to cover the rest of the issues.





AASPIRE

# Healthcare Toolkit

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## Healthcare: After the Visit

### Contents

- What is this topic about?
- What might I do if I have questions after the visit is over?
- What might I do if the provider asked for a follow-up visit?
- What might I do if the provider made a referral to another provider or specialist?
- What might I do if the provider ordered lab tests?
- What might I do if the provider prescribed medications?
- What might I do if the provider asked me to track things, like my symptoms?
- What might I need to know about taking care of my health condition(s) at home?
- If I need assistance to do these types of things, what might I do?
- My provider often seems rushed at the end of visits, how might I get all my questions answered?
- Summary and Tips

# Healthcare: After the Visit

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[www.aaspire.org](http://www.aaspire.org)

Last Updated September 29, 2015

## 1 What is this topic about?

This topic is about things that may need to be done after a visit with a healthcare provider. These things might include:

- Contacting your healthcare provider if you have questions after the visit
- Making a follow-up appointment with your healthcare provider
- Making an appointment with a different healthcare provider or a specialist (a referral)
- Getting a lab, x-ray, or other test
- Filling a prescription, getting or taking a medication
- Tracking your symptoms
- Taking care of your health condition(s) at home

The [After the Visit Worksheet](#) has spaces to organize information about these things.

## **2 What might I do if I have questions after the visit is over?**

You might think of questions for your healthcare provider after the visit is over. For example, you might need more information about something that was talked about during the visit. Or you might realize you don't have good instructions for how to do something at home to manage your health. If you have questions that come up after your visit, you can contact someone to get your questions answered. Before you leave the clinic or office on the day of your visit, ask your healthcare provider or the front desk staff who you can contact if you have questions after you get home. Ask how to contact the person. If you are given a contact method that does not work for you (for example, they give you a phone number and you do not use the telephone), ask if there is a different way, and tell them what methods might work better for you. It doesn't matter how long after the appointment you realize you have more questions. What matters is that you get the information and care that you need. Contact your provider's office and tell them that you have some questions about your last visit.

## **3 What might I do if the provider asked for a follow-up visit?**

It is always a good idea to know when your health care provider wants you to come back to see him or her. Often your provider will tell you this information, but you may want to ask if he or she does not tell you first. Follow-up appointments are often made to see if a medication is helping, to see if a problem has gotten better or worse, or to tend to an injury. If a follow-up appointment is needed, make sure you know this information:

- When should I make the follow-up appointment for?
- How do I make a follow-up appointment?

- Is there anything special I should do before the follow-up appointment or bring to the follow-up appointment?

You might be able to schedule the follow-up appointment with the clinic or office staff before you leave the clinic or office.

#### **4 What might I do if the provider made a referral to another provider or specialist?**

Your healthcare provider might ask you to make an appointment with a different healthcare provider, or with a specialist or a specialty department. Healthcare providers make referrals when your health problem needs the care of someone who specializes in that kind of problem. For example, a healthcare provider might refer you to a dermatologist for an unusual rash. If you were given a referral to another provider, clinic, or department, you may need to make an appointment with the person or department you were referred to or this may be arranged for you. Check whose job it is to schedule the new appointment—yours or theirs. The office staff can tell you. Good information to know is:

- What is the name of the person, clinic, or department I'm supposed to see?
- Why have I been referred to this other provider?
- Do I call them or do they call me?
- Who do I contact to make the appointment?
- How do I make the appointment?
- How quickly do I need to be seen by this other provider?
- When should I expect to hear back from this other provider?

- What should I do if I don't hear back from this other provider, or if they cannot see me in time?
- Should I bring anything special with me when I go to this other provider?

If the referral is to someone in the same clinic or facility as your healthcare provider, you might be able to make the referral appointment with the front desk staff before you leave the office. Make sure the provider you have been referred to knows about any accommodation needs that you have. You might also want to ask your healthcare provider to talk to the specialist or department about your needs.

## **5 What might I do if the provider ordered lab tests?**

Your provider may order labs, X-rays, or other tests. Some examples of labs and tests are blood draws, urine samples, or ultrasounds. Some tests might be done the same day as your healthcare appointment and not need any special scheduling. Other tests you might need to schedule later, or with another person or department. It will depend on the test and the reason for the test. If your healthcare provider has ordered labs, X-rays, or other tests, and they are not going to be done right away before you leave the office, make sure you know the information below. Note that not all of these questions might apply to the test or procedure you need.

- What is the name of the test or procedure?
- Where do I go to have the test or procedure done?
- Do I need to do the test or procedure at a special time or day? If so, when?
- Do I just show up for the test or procedure, or do I have to schedule an appointment?

- Who do I schedule the appointment with, and how do I do it?
- Are there special instructions? Example: do not eat anything for 12 hours before the test (this is called fasting).
- What will the test or procedure be like? Will there be strange sounds or sensations? Will it hurt?
- How will I find out the results of the test?

If you have insurance, you may also want to ask whether or not your insurance will cover the test or procedure. You may need to get this information from your insurance provider. If the lab, x-ray, or test will be done in the same clinic or facility as your healthcare provider, you might be able to make the appointment with the front desk staff before you leave the office. Make sure the people doing the labs, x-rays, or tests know about any accommodation needs that you have. You might also want to ask your healthcare provider to talk to the specialist or department about your needs. Ask your healthcare provider for help preparing for labs or tests, if you need it.

## **6 What might I do if the provider prescribed medications?**

Your healthcare provider might ask you to take a medication or use a medicinal cream or patch. The medication could be prescription only, or it might be something you can buy in stores without a prescription (sometimes called "over the counter" medicine). For any kind of medication, make sure you feel comfortable with how to use it before you leave the office. You should try to answer all of the following questions:

- What is the name of the medication?
- How many pills or how much liquid do I take at a time? If it's a cream, how much do I put on at a time? If it is a patch, where do I put it on my skin?

- How many times a day do I take or use the medicine?
- What time or times of day should I take or use the medicine?
- Does it matter if I take the medicine immediately before or after eating?
- Do I take or use the medicine only when I have a symptom or do I take it regularly on a schedule?
- When do I stop taking or using the medicine?
- What side effects should I look out for?
- What do I do if there are side effects?
- Are there risks of interactions (bad reactions) with sunlight, my other medicines, or foods I may eat?
- Should I avoid any particular activities while I'm taking this medication?
- Do I need to refrigerate the medication, or store it in a special way?

If the provider prescribed medications, you will also need to know about the prescription, and about refills. It is a good idea to know the name, address, and phone number of your preferred pharmacy, if you have one. You may want to give that information to your provider. Some things to know before you leave the office are:

- Has the prescription been faxed / e-prescribed / called in to the pharmacy, or do I need a paper copy of the prescription?
- If the prescription has been faxed, e-prescribed, or called in, where is the pharmacy?
- If I am getting a paper copy of the prescription, is there a particular pharmacy I need to take this to, or can I take it to any pharmacy?
- How do I get refills, if I need them?

When you pick up your medication at the pharmacy you can have a short conversation with the pharmacist about the medication. You may want to ask these questions again, or any other questions about the medication:

- Are there any special warnings about this medication?
- What are the side effects?
- What do I do if I experience side effects?

It can also be good to tell the pharmacist what the instructions are for taking or using the medication, in your own words. The pharmacist can help to make sure you have the right instructions. When you start taking a medication, you may want to think about how you might remember to take it at the right times. Here are some ways that people remind themselves:

- Set a daily alarm clock or cell phone alarm
- Use a pill box that has days of the week compartments to remind you
- Put your medicine in a place where you are likely to see it
- Mark your calendar or daily journal when you have taken it
- Make yourself a reminder sign and place it somewhere you are likely to see it
- Ask someone to help remind you

## **7 What might I do if the provider asked me to track things, like my symptoms?**

Your healthcare provider might ask you to track your symptoms. For example, you might be asked to keep a pain diary, a mood diary, or note when your symptoms become better or worse. Symptom tracking is usually used to



monitor the progress of a condition, to better understand a condition, or to see if a medication or treatment is working. There are a lot of different options for symptom tracking. You might need to try more than one way, or even invent your own way, in order to find a symptom tracking system that works for you. Here are some ideas:

- Use a paper calendar or day planner
- Use a paper diary
- Use a symptom tracker online. Examples:
  - Symptom tracker at the [Mayo Clinic](#)
  - Symptom tracker at [WebMD.com](#)
- Use a symptom tracker program on your computer (search the Internet for "symptom tracker software")
- Use a symptom tracker app on your smart phone, tablet, or PDA (search your device's app store for "symptom tracker")
- Use an audio or video diary (for example, with a voice recorder, with the recorder and camera on a smart phone or computer)

For many of these kinds of trackers, symptoms can be noted in words (for example "mild" or "severe") or they can be noted with pictures (for example, a smiley face or a sad face). Remembering to keep track of symptoms can be hard for a lot of people. Here are some ideas for how to remember to use a symptom tracker:

- Set a timer or alarm to go off when it's time to use the symptom tracker.
- Pick a time of day when you are usually not busy, and always track your symptoms at that same time of day (for example, after dinner, before you brush your teeth, or at noon).
- Ask a friend, a family member, or someone you live with to help remind you.

- If you keep a daily planner, a visual schedule, reminder notes, or a daily to-do list, add working on your symptom tracker to it.

## **8 What might I need to know about taking care of my health condition(s) at home?**

Your healthcare provider may ask you to do things at home to manage your health condition or conditions. For example, you may be asked to keep a pain diary, to eat a special diet, or to use some kind of medical equipment like a crutch or a splint. Before you leave the office, make sure you have instructions that you understand for what to do at home. The instructions might be given to you by a nurse or someone else in the office or clinic who is not your primary healthcare provider. It can be helpful to do a "teach back" with the person who gives you the instructions. In a "teach back," first someone explains or shows you how to do something. Then you explain or show them how to do that same thing, in your own words. Teaching often helps people to learn.

## **9 If I need assistance to do these types of things, what might I do?**

Your provider's office may be able to help you with some of the things you need to do after the visit. Ask the nurse, care manager or the front desk staff if they can help you. Not all offices will be able to help you with these things, but it is always worth asking. Some things your provider's office may be able to help you with are:

**Scheduling Appointments** - If your follow-up, referral, test, or pharmacy pickup is in the same office, clinic, or medical facility as your healthcare provider, they probably can schedule the appointment for you. You can also ask if the office has an online appointment tool or other ways to make setting up appointments easier. Some providers' offices will call you and remind you

when it's time to set up a follow-up or other appointment. Each office has different tools and policies, so ask what is available for help with scheduling appointments.

**Reminders** - Ask the office staff if they do reminder calls or emails. If they do, ask them about any accommodations you might need regarding reminders for your appointment. Some offices or clinics may have people who can help with reminders to pick up a medication from the pharmacy.

**Social Services** - Some providers work with social workers or can help you network with other social services like vocational rehabilitation, food stamps, housing or other health and human services. If you have basic needs that are not getting met in your daily life, talk about that with your healthcare provider. They may have some resources or ideas.

**Transportation** - Ask your healthcare provider's office if they can help you connect with transportation options through your regional transportation system or volunteer driver programs.

**Directions** - Your provider's office may have information sheets that offer directions to get to places you'll need to go for referrals or tests. If the office or clinic is large enough, like a clinic that is part of a major hospital, it may also have a map of the whole facility. Someone from the office may also be able to help guide you to a place you need to go in the building, like the X-ray or radiology department.

## **10 My provider often seems rushed at the end of visits, how might I get all my questions answered?**

There are a lot of questions to be answered about follow-up care like labs, medications, or at-home care. Sometimes providers may run out of time at the end of a visit and need to go see other patients. If it seems like the provider is in a rush or if the provider is ending your visit without answering all

your questions, make it clear you still have more questions. Find out what the best way would be to get your questions answered. For example, you might say:

*"I know you don't have much time now, but I still have some important questions about my follow-up plans. What would be the best way for me to get them answered? Is there someone in your office who could help me or is there a way I can be in touch with you later? Thanks."*

## **11 Summary and Tips**

If you have questions after your visit, it is OK to contact your healthcare provider and ask them. Before you leave the medical office, get information for who to contact if you have questions, and how to contact them. Things your healthcare provider might ask you to do after your visit are:

- Make a follow-up appointment to see how things are going
- Go see another healthcare provider or specialist
- Have a lab, x-ray, or other test done
- Take or use a medication
- Keep track of your symptoms
- Do something at home to take care of your health condition

Try to get all of the information you need about any of these things you've been asked to do before you leave the office. Make sure you understand any instructions for taking medication, preparing for labs, or doing things at home. If you think you will need help doing any of the things you have been asked to do, talk to your healthcare provider or to the nurse about it. Your healthcare provider's office may be able to help in other ways besides medical care.

Ask your provider's office if they can help you with directions, transportation, reminders, social services, or making appointments. If your provider seems too rushed at the end of a visit to answer your questions properly, ask them what the best way will be for you to get them answered later. The [After the Visit Worksheet](#) has spaces to organize information about these things.